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Racial Differences in Trust and Risk Disclosure Preferences Among Older Registered Research Volunteers Screened for Prodromal Synucleinopathies

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Abstract

Background/Objectives: The equitable enrollment of minority participants in synucleinopathy trials is an emerging public health concern. Differing views regarding risk disclosure may influence research involvement in at-risk adults.

Methods: We conducted a brief mailed survey, including questions about trust and hypothetical risk disclosure preferences, to 100 participants in the Healthier Black Elders Center cohort in Detroit, MI and 100 participants in the Claude D. Pepper Older Americans Independence Center Research Participant Program at the University of Michigan.

Results: 125 recipients without a diagnosis of a neurodegenerative disorder returned the survey, 52 (41.6%) of whom identified as being Black or African American. Black respondents reported less trust in medical providers (t=2.02, p=0.045) and medical researchers (t=2.52, p=0.013) and a greater desire to be informed about the presence of unchangeable risk factors for neurodegenerative disorders (t=2.02, p=0.045).

Conclusions: These findings have implications for the recruitment of representative populations in prodromal neurodegenerative research.

Keywords

lewy body, race, survey, risk disclosure, African American

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Introduction

Prodromal clinical trials commonly test putative dementia-prevention approaches in subjects at risk for Alzheimer's disease (AD) and Mild Cognitive Impairment (MCI). Similar prodromal trials are an emerging concept in common alpha-synucleinopathies including Parkinson disease (PD) and Dementia with Lewy Bodies (DLB). Improving the enrollment of racially diverse and representative cohorts in neurodegenerative disease trials has a compelling scientific rationale and is of increasing societal interest. Nevertheless, recent dementia trials continue to be characterized by marked underrepresentation of Black or African American participants.

There are multiple contributors to the persistence of such disparities including systematic inequities that influence access to tertiary care-affiliated research centers, suboptimal

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trial design and recruitment approaches, and a mismatch in incentives between those of industry trial sponsors and those most relevant to public health at large. Recent studies on prodromal synucleinopathies have highlighted uncertainty in whether and how best to counsel patients and research participants with isolated rapid eye movement (REM) sleep behavior disorder (iRBD) on their elevated risk for neurodegenerative conditions including synucleinopathies (Dommershuijsen et al., 2020) Risk disclosure preferences for a future disease are likely to influence how receptive a given individual is to enrollment in a prodromal trial aimed at forestalling that future disease state. To better understand the influence of race on risk disclosure preferences, we conducted a mailed survey of a multiracial cohort of older adults.

Methods

As a recruitment component of an over-arching neuroimaging study aimed at understanding progression markers for prodromal alpha-synucleinopathies (R56AG065529), we conducted a cross-sectional one-time mailed survey to 200 total participants—100 in each group—aimed at identifying eligible and interested participants from two separate groups of healthy older adults. The survey itself consisted of a one-page cover letter, a 4-item olfactory test, a small cash stipend ($2.00 USD), return postage materials, and a brief 2-page questionnaire focused on identifying individuals with prodromal features of alpha-synucleinopathies including hyposmia and symptoms of RBD. Surveys were mailed in 2021 to the addresses on file with each respective registry and were not followed with any additional contact from the study team.

Survey recipients in each group were registered adults age 60 and older who had expressed an interest in participating in studies focused on health and aging. One cohort was the Healthier Black Elders Center (HBEC) cohort centered in Detroit, MI USA. The HBEC is a component of the US National Institute on Aging (NIA)-funded Michigan Center for Urban African American Aging Research (MCUAAAR), a community-based participatory approach to research recruitment of a predominantly African American cohort in Detroit, Michigan with administrative effort shared between the University of Michigan (UM), Wayne State University, and Michigan State University(Mitchell et al., 2020). The second survey cohort was the Claude D. Pepper Older Americans Independence Center Research Participant Program at UM. This NIA-funded recruitment cohort consists of older adults living in or adjacent to Washtenaw County, Michigan who have expressed an interest in hearing more about research studies.

Survey recipients were asked about symptoms of hyposmia, a known risk factor for parkinsonian conditions (Baba et al., 2012), and were asked to complete the 4-item scratch-and-sniff, multiple-choice National Health and Nutrition Examination Survey (NHANES) pocket smell test.(Liu et al., 2016) Survey recipients were also asked about neurological diagnoses and symptoms, frequency of ongoing medical and neurological care, trust of medical providers and researchers, and about hypothetical preferences related to risk disclosure for future neurodegenerative disorders. On a 1-5 Likert scale, with responses ranging from strongly agree to strongly disagree, survey recipients were asked their opinions on the following two statements: "I trust my doctor to put my medical needs above all other considerations when treating my medical problems." and "I trust medical researchers to be ethical and honest in their work." On an analogous 1–10 Likert scale ranging from strongly agree (1) to strongly disagree (10), recipients were asked their opinions about the following statement "If I had a fixed (i.e. not changeable) risk factor that put me at higher risk for developing a neurodegenerative disease, I would want to know." We compared responses between subjects who self-identified their race as Black or African American versus others. Responses were treated as ordinal continuous variables. Two sample t-test and chi-square testing were performed to compare characteristics and survey responses between the two groups. All analyses were performed using STATA 15 (College Station, TX). This survey was approved by UM IRBMED and granted a waiver of documented informed consent.

Results

133 out of 200 survey recipients returned the mailed survey. 125 of these 133 did not have a co-existing diagnosis of a neurodegenerative disorder. 52/125 (41.6%) identified as being Black or African American. There were no differences between groups in hyposmia features, RBD symptoms, or self-reported existing diagnoses of sleep apnea. Symptoms of hyposmia were noted in 6/49 (12.2%) Black or African American respondents and 7/69 (10.1%) of non-Black respondents. 110 total respondents completed this question and the NHANES 4-item pocket smell test. Interestingly, participants who acknowledged symptoms of a declining sense of smell did not perform appreciably worse on the 4-item smell test [mean number of correct responses: (+) symptoms of hyposmia (n=29) 3.38 (SD=1.24) versus (−) symptoms of hyposmia (n=89) 3.56 (SD: 0.78)]. These findings did not differ by race category. Black respondents were more likely to be women and were more likely to have seen a primary care physician and/or neurologist in recent months compared to non-Black respondents (Table 1). Compared to non-Black respondents, Black respondents reported less trust in medical providers (t=2.02, p=0.045) and medical researchers (t=2.52, p=0.013) and a greater desire to be informed about the presence of fixed/unchangeable risk factors for neurodegenerative disorders (t=2.02, p=0.045).

Discussion

Our findings add several new elements to existing literature on the topic of screening for prodromal neurodegenerative

Table 1. ■■■.

	Black or African American (*n*=52)	Not Black or African American (*n*=73)	t-test/Chi-Square; *p*-value
Age	76.3 (6.6) (*n*=50)	77.8 (6.4) (*n*=72)	t=1.20, *p*=0.23
Gender	49 W/3M	43 W/30M	Chi-square: 19.50, *p*<0.001
Symptoms of hyposmia	43=No 6=Yes (*n*=49)	54=No 15=Yes (*n*=69)	Chi-square: 1.77, *p*=0.18
Number of correct responses on NHANES 4-item pocket smell test	3.43 (0.96) (*n*=46)	3.51 (0.95) (*n*=71)	t=0.40, *p*=0.69
Symptoms of RBD	45=No 6=Yes (*n*=51)	62=No 7=Yes (*n*=69)	Chi-square: 0.08, *p*=0.78
History of sleep apnea	39=No 13 =Yes	54 = No 19=Yes	Chi-square: 0.02, *p*=0.90
Recent frequency of primary care provider visits	Within the last 3 months=37 Within 3–12 months=13 More than 12 months ago=2 Never=0	Within the last 3 months=34 Within 3–12 months=32 More than 12 months ago=7 Never=0	Chi-square: 7.61, *p*=0.02
Recent frequency of neurologist care	Within the last 3 months=4 Within 3–12 months=6 More than 12 months ago=7 Never=28 (*n*=45)	Within the last 3 months=0 Within 3–12 months=5 More than 12 months ago=17 Never=45 (*n*=67)	Chi-square: 8.21, *p*=0.04
Trust in medical providers	Strongly Agree=21 Agree=20 Neutral=9 Disagree=0 Strongly Disagree=1 (*n*=51)	Strongly Agree=35 Agree=35 Neutral=3 Disagree=0 Strongly Disagree=0 (*n*=73)	t=2.02, *p*=0.045
Trust in medical researchers	Strongly Agree=20 Agree=21 Neutral=8 Disagree=2 Strongly Disagree=0 (*n*=51)	Strongly Agree=35 Agree=37 Neutral=1 Disagree=0 Strongly Disagree=0 (*n*=73)	t=2.52, *p*=0.013
Interest in wanting to know about personal risk factors for neurodegenerative diseases*	1.38 (0.81) *n*=50	1.93 (1.81) *n*=73	t=2.02, *p*=0.045

*Lower numerical values denote greater interest in knowing.

conditions. First, we report that Black or African American older adults interested in participating in clinical research do not appear to have differing rates of hyposmia, sleep apnea, or RBD symptoms compared to non-Black older adults. Future screening methods focusing on these 3 known clinical risk factors for parkinsonian conditions (Baba et al., 2012; Boot et al., 2012; Yeh et al., 2016) aren't likely to be confounded by racial differences in prevalence rates. Second, even among this enriched cohort of participants, all of whom carry a pre-stated interest in hearing from clinical researchers, survey respondents who identified as Black or African American reported less trust in medical researchers compared to their non-Black/African American counterparts. Third, survey respondents who identified as Black or African American expressed a greater desire to be informed about unchangeable risk factors for neurodegenerative disorders compared to non-Black/African American respondents. This latter finding related to varying opinions on transparency with risk counseling has not been charachterized previously in racially diverse cohorts of people at risk for neurodegenerative disorders. Our

findings have implications for trial design and recruitment practices in neurodegenerative disease clinical trials moving forward.

Interestingly, Black or African American respondents acknowledged a higher frequency of both Primary care and Neurology care than non-Black/African Americans. These findings support the idea that clinic-based recruitment approach may be an effective way to recruit a racial diverse cohort of prodromal neurodegenerative participants compared to other alternatives including less-personal, mailed screening and recruitment approaches.

Research focused on cancer has suggested that race-specific barriers to trial participation among African Americans include lower awareness of clinical trials and a stronger perception of the experimental nature of trial participation as well as structural barriers to participation including transportation barriers and limited access to care.(Rivers et al., 2013) A prior study has suggested African American and Chinese American adults may be more likely to view PD as a core part of normal aging than whites.(Pan et al., 2014)

What little we know about risk counseling in individuals with static synucleinopathy risk factors who are at risk of developing PD or DLB—factors including the presence of iRBD or genetic risk alleles—suggests there exists substantial variability in participant preferences about how such risk is disclosed.(Dahodwala et al., 2007) Such provider and participant concerns are likely to be central factors in recruitment efforts for prodromal synucleinopathy trials. Differences in genetic risk disclosure preferences may also vary between racial groups and have been better characterized in cancer literature where such testing can inform an individual's understanding of cancer risk, aggressiveness, and response to therapies. A prior study in prostate cancer suggested that Black men may be more inclined to learn their genetic testing results even when risk was lower whereas all participants favored risk disclosure when risk was higher.(Roy et al., 2020) Our survey's findings are consistent with this possibility. A previous PD interventional study that focused on improving community-physician referrals failed to yield an improvement in the racial and ethnic make-up of a trial's cohort.(Tilley et al., 2012) It is possible that provider-focused interventions may be less effective than participant-focused approaches for improving the enrollment of racially diverse cohorts in PD.

This study has several relevant limitations. Black respondents were disproportionately female compared to non-black respondents. This gender skew may have impacted our findings. It is also worth noting that Black survey respondents were more likely to have seen a primary care physician or neurologist in recent months compared to non-Black respondents. We also did not collect information regarding level of health education or factors related to socioeconomic status from respondents. Differences in frequency of outpatient evaluations, health education, and socioeconomic status, may underlie some of intergroup differences seen between races in this survey which may or may not be generalizable to the broader population at large. The fact that our survey findings are in line with previous data studying the role of race and self-reported research trust, however, suggests that our findings are likely to reflect real-world preferences. Strengths of our approach include the multiracial nature of this cohort in geographic proximity to our medical center and the combined use of a mailed survey, capable of assessing prodromal neurodegenerative symptoms, and a mailed olfactory test, capable of assessing prodromal neurodegenerative signs.

Prospective patient-facing, studies focused specifically on the views of underrepresented racial minorities related to participation in synucleinopathy research are needed to better characterize actionable steps needed to improve the racial diversity of prodromal synucleinopathy research cohorts. Improving the racial make-up of prodromal synucleinopathy research cohorts is an essential component of the field's scientific goals.

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Declaration of Conflicting Interests

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