


2023

What is your why? A qualitative study about motivational differences of Latinos/Hispanics and African American/Black in a computerized cognitive training program to prevent Alzheimer's Disease

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MOTIVATIONS TO PARTICIPATE IN ADRD PREVENTION STUDY

**What is your why? A qualitative study about motivational differences of Latinos/Hispanics
and African American/Black in a computerized cognitive training program to prevent
Alzheimer's Disease**

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A thesis submitted to the Department of Psychology in partial fulfillment of the requirements for
the degree of Master of Science in Psychological Science

UNIVERSITY OF NORTH FLORIDA

COLLEGE OF ARTS AND SCIENCES

February, 2022

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Abstract

Recruitment of diverse populations is a major barrier in advancing clinical research (Areán & Gallagher-Thompson, 1993; Areán & Alvidrez, 2003). The need to increase racial diversity is imperative due to the substantial growth of historically marginalized racial communities in the United States (Weinstein et al., 2017). Despite researchers' efforts to increase racial/ethnic representation in clinical trials, there is still a lack of understanding of the best practices to recruit racial/ethnic minorities in clinical trials. The current study explores the qualitative motivations of why research participants (aged 65+ years old) volunteered for an Alzheimer's Disease (AD) prevention clinical trial. Racial/ethnic differences are explored using case-controlled matching between White/Caucasians (n=210; M = 71.01 years, SD = 4.41) and African Americans (n=210; M = 71.26 years, SD = 4.47), and between non-Hispanics (n = 158; M = 71.13, SD = 5.33), and Hispanics (n = 157; M = 71.48 years, SD = 5.14). Compared to non-Hispanics, results indicated Hispanics were more likely report the following as motivators: concerns about brain health and aging (59.7%; $\chi^2 = 3.99$, $p < .05$, $\phi = .11$) and improvement of personal brain health (60.9%; $\chi^2 = 4.30$, $p < .05$, $\phi = .12$). African Americans were also more likely to report concerns about brain health (59.6%; $\chi^2 = 4.66$, $p < .05$, $\phi = .12$) compared to White/Caucasians. Results suggest concerns of cognitive decline and brain health are common motivators to participate in AD research, which introduces opportunities to better strategize participant recruitment in clinical research (Coley et al., 2021).

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Dementia is an umbrella term for declining memory, reasoning, and thinking skills. Alzheimer's Disease (AD) is a type of Dementia or degenerative brain disease caused by brain changes due to cell damage (Alzheimer's Association, 2022). AD has been the focus of research for many years as it is one of the most common cognitive diseases for the aging population in the United States (Ritchie et al., 2015; Vernooij-Dassen et al., 2021; Pickett et al., 2018). Currently, 6.5 million individuals in the United States, ages 65 years and older, have AD. This number will only continue to grow as projections for 2050 indicate that 130 million people will have the disease (Wortmann, 2016). Historically marginalized groups have a higher risk of developing AD. Latinos/Hispanics are 50% more likely, and Black/African Americans are 40% more likely than non-Latino whites to develop AD (Denny et al., 2020; USC Edward R. Roybal Institute on Aging, 2016; Vega et al., 2017). High population projection numbers for historically underrepresented racial and ethnic minority groups and a high risk for Dementia in Black/African Americans and Latinos/Hispanics highlight the need for AD-related research, treatments, and policies that include the diversity of the United States population.

AD development and diagnosis based solely on genetic risk factors, including tau pathologies, amyloid deposition, APOE, and neurodegeneration, is complex in minority groups (Chin et al., 2011; Clark et al., 2003). For example, one previous study found that while

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Black/African Americans individuals had similar amyloid levels compared to White/Caucasian individuals, Black/African Americans had lower tau pathology (Gleason et al., 2021).

Additionally, though African American/Black individuals revealed less cerebral volume reduction and less degeneration than White/Caucasian individuals, the differences were insignificant once sociodemographic factors were included (Gleason et al., 2021). Race and ethnicity are not biological concepts, which means there is extensive genetic variability within historically marginalized groups. This variability highlights the need for heterogeneity within racial and ethnic samples in AD research to provide a more comprehensive solution that includes distal and proximal social factors in Dementia literature (Lines et al., 2014). A better approach to explaining AD is the interaction of different biological (i.e., genetics) and environmental factors (i.e., socioeconomic status, cultural differences, discrimination) that influence directly, or indirectly, AD outcomes, risk, treatment, and knowledge (Lines et al., 2014). Illustrated by probabilistic epigenetics, the genotype (i.e., biological factors) might react or be influenced by environmental factors and vice versa. The bidirectional influence of the environment and the genotype ultimately impact the phenotypic expression of biological factors and, consequently, the development of the disease (Gottlieb, 2007).

For example, historically marginalized groups present more impairments during diagnosis, including more hallucinations, expressed anger, and wondering. One potential reason is that individuals seek care at later progress stages of AD (Livney et al., 2011; Lines et al., 2014). Distal social factors (e.g., discrimination experiences, cultural and language barriers, and the socioeconomic position) may explain delays in proximal social factors (e.g., seeking medical help, lack of access to health resources, and comorbidity with other diseases). Individual mediators (e.g., availability of resources, psychological stressors, cognitive engagement) explain

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distal and proximal social factors impact in the development and diagnosis of AD (Cooper et al., 2010; Glymour et al., 2008). In addition, life adversity variables like poverty, poor health, hunger, chronic stress, and lack of education influence cognitive impairment in later life (Zhang et al., 2016).

On the other hand, education is a protective factor for Dementia, which relates to distal social factors like discrimination. A more significant amount and a higher quality of education lead to better cognitive functioning /engagement and a slower decline of cognitive skills (Jefferson et al., 2011; Reuser et al., 2011). For historically marginalized groups, the unequal and segregated education structure, in addition to low socioeconomic status and residential location, influences the quality of education and the subsequent protection from AD (Glymour et al., 2008). Even though extensive research exists in explaining social and biological factors related to AD, inconclusive results, and the lack of incorporation of the intersectionality of both factors might prevent a further understanding of AD in historically marginalized groups.

AD research is not an exception to the existent crisis of the lack of representation of historically marginalized groups in clinical research, consequently exacerbating health disparities, misdiagnosis in AD, and false perception of the illness (Askari et al., 2017; Babulal et al., 2018; Dubé et al., 2019; Gilmore-Bykovskiy et al., 2019; Mayeda et al., 2016). The cyclical pattern will continue if representation issues persist, consequently impacting the applicability of disease knowledge to medical and research practice. For example, even though recent evidence suggests that Latinos/Hispanics and Black/African Americans are more likely than whites to develop AD A lack of participation exists as less than 1% of Latinos/Hispanics and 7.3% of Black/African Americans participate in clinical trials or research (USC Edward R. Roybal Institute on Aging, 2016; Denny et al., 2020). Different social, health, and cultural

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factors, including stigma, institutionalized racism, cultural differences, education, socioeconomic, and health disparities, influence the intersectionality of higher risk of AD and the low participation in clinical research in historically marginalized groups (Alzheimer's Association. 2021; Kukull et al., 2022; Glymour et al., 2008).

Understanding the motivations of historically marginalized groups who participate in Dementia-related research studies is essential because it gives researchers insight into the weighting of benefits and barriers participants perceive when deciding to participate in research (Verheggen et al., 1998). Furthermore, understanding the motivation to participate can help reduce barriers present in AD research, including slow recruitment, lack of target enrollment, and attrition in follow-up longitudinal research (Ashford et al., 2020). Furthermore, a better understanding can highlight prominent barriers associated with geriatric research like illness, death, institutionalization, difficulty arranging transportation to visits, and managing weather changes (Neugroschl et al., 2014).

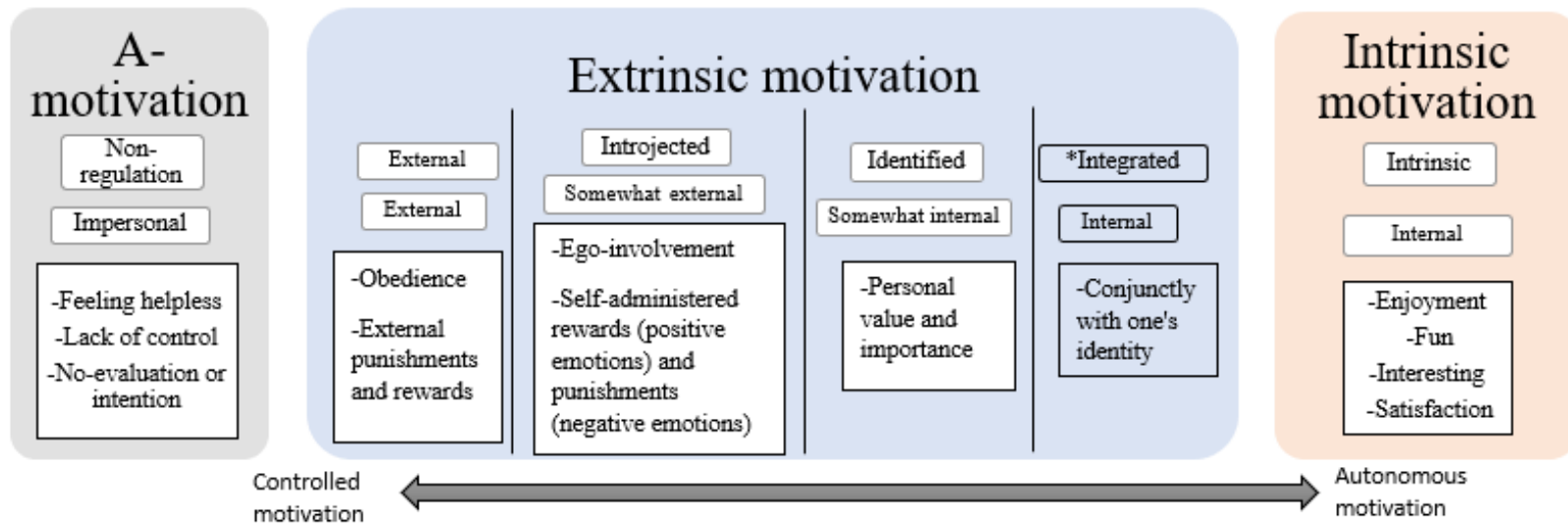
Motivation for Participating in Dementia Research Studies

Motivation is the force that initiates, directs, and sustains behavior (Petri, 1981). The basic categorization of motivation includes the intrinsic (i.e., doing an activity for pure pleasure or interest) compared to the extrinsic (i.e., doing the activity to achieve a particular outcome; Deci, 1971). The evolution of the conceptualization of motivation expanded with a new category, "amotivation," defined as the lack of all motivation (Deci, 1971). Self-Determination Theory (Ryan & Deci, 2000) expands on the basic categorization of motivation (i.e., external and internal) by including several types of extrinsic motivators. The external, introjected, identified, and integrated motivations were the new extrinsic categorizations that present a continuum of self-determination, moving from controlled to autonomous motivation (Ryan & Deci, 2000).

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Figure 1

Types of Motivations based on Self-Determination Theory



**Note:* Integrated category is faded, as previous evidence suggests it is highly correlated to intrinsic (Van den Broeck et al., 2021)

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The external category includes rewards and punishments administered by an external source and has the most controlled motivation (Van den Broeck et al., 2021). For instance, providing participants with monetary compensation in the research setting is an example of this external source. In comparison, the introjected category involves ego and self-esteem and consists of avoiding negative feelings (i.e., guilt or shame) while increasing positive feelings (i.e., pride). The introjected category is controlled and pressured by internal forces and related to reputational gains (Deci & Ryan, 2000). For example, interactions with the research team can be a motivator during the retention stage (Neugroschl et al., 2014). They could be an example of introjection if these interactions result in feelings of guilt, shame, or pride. Meanwhile, aging research shows that the most frequent reason why older adults with Mild Cognitive Impairment (MCI), Dementia, and AD are “motivated” to continue in longitudinal studies is related to extrinsic intrinsic regulation motivation. For instance, previous research evaluating the motivation to participate in clinical research found that 56% of older adults (>75 years old) reported benefitting society as their primary motivation (Marcantonio et al., 2008).

Another category in the extrinsic motivators is identified regulation, which involves people who engage in activities because they are meaningful and essential to them (Van den Broeck et al., 2021). For example, an older adult playing cards to keep their mind sharp is an extrinsic motivation because the activity has a goal, and the behavior is self-determined since the individual considers playing cards beneficial and valuable (Vallerand & O'Connor, 1989). On the other hand, integrated motivation is when the motivator is integrated with personal values and completely internalized (Deci & Ryan, 2000). Integrated motivation is considered the most autonomous motivation and similar to intrinsic motivation, where motivation is due to pure enjoyment, fun, and interest. An example of this type of motivation is participating in health

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research due to self-interest and knowledge (Neugroschl et al., 2014). The difference between extrinsic integrated motivation and intrinsic motivation is that motivational internalized reasons are instruments to reach an outcome outside the activity or behavior itself (Van den Broeck et al., 2021).

Motivation with more significant amounts of self-determination like internal and extrinsic integration and identified regulation motivators is associated with greater cognitive flexibility, conceptual learning, more interest, self-esteem, positivism, and higher levels of life satisfaction, creativity, and performance (Vallerand & O'Connor, 1989). The main reason to participate in research is altruism (45%), including wanting to find a cure and give back to society, followed by concern about their health (42%) which illustrates the effectiveness and positive outcomes that high determination motivators have in research recruitment (Neugroschl et al., 2014). On the other hand, external motivators with low self-determination, including rewards such as healthcare (23 %) and money (4.6 %), were the lowest reported motivators (Bardach et al., 2020).

The Self-Determination Theory has been criticized due to the emphasis on individualism and autonomy, impacting the theory's applicability and generalization in collectivistic cultures, common in Latinos/Hispanics and Black/African Americans. Motivation for these groups can include social pressure to avoid guilt and shame, suggesting introjected and external motivation categorization might be more fitting (Van den Broeck et al., 2021). In contrast, existing literature has shown the universal application of the Self-Determination theoretical concepts in collectivistic cultures, including the Hispanic/Latino and Asian communities (Church et al., 2014; Ranjit et al., 2017). The variability of the theory and results in different studies is due to

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individual personal values and self-construal rather than culture alone (Ranjit et al., 2017; Kaur & Noman, 2020)

Most research about the motivation of participants in clinical research studies involving Dementia and other health-related topics lacks Latinos/Hispanics and African American/Black communities, feeding into a cyclical lack of participation, representation, and understanding of recruitment /retention of these groups (Lang et al., 2013; Perreira et al., 2020; Hohl et al., 2014). The Hispanic Community Health Study/Study of Latinos longitudinal health research found the highest motivators for Latinos/Hispanics were learning about health status and helping the community. In addition, access to free medical services and referrals, having interviews available in Spanish, and having a family or friend referral were also common motivators (Perreira et al., 2020). Common motivators like referrals from family and friends, the need to help the community, and access to free medical services highlight introjected and external motivations of the Self-Determination Theory as a better fit for collectivistic cultures. The prioritization of the group's well-being and in-group prosocial behaviors explains the possible fit of extrinsic introjected and external motivators in collectivistic cultures (Markus & Kitayama, 2010; Tsai et al., 2021).

On the other hand, learning about health status shows the presence of extrinsic identified regulation motivation. Meanwhile, external motivators, including monetary compensation, had inconsistent findings. For Black/African Americans, monetary compensation was the second-highest motivator. In contrast, Latinos/Hispanics rated monetary compensation as a lower motivation (41%) which was an additional benefit to other primary motivators, like altruism (Lang et al., 2013; Perreira et al., 2020; Hohl et al., 2014). Both external and extrinsic-identified

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motivation findings contrast the possible limitation of specific motivational categories and Self-Determination Theory's applicability to other cultures.

Altruism is the highest motivator in AD and related Dementias research, regardless of ethnicity. At the same time, altruism is present in the different motivators of why people volunteer in activities (Burns et al., 2006), which stresses the importance of differentiating altruism into more specific categories. Recruitment communication and marketing need to reflect how research can contribute to altruism. Specifically, providing an immediate and clear personal advantage and the benefit to society and the community should be at the forefront of recruitment efforts (Bardach et al., 2020).

Incorporating personal background and social context variables when explaining the decision-making process for participating in research, including motivation, is fundamental as ethnic, cultural, and developmental diversity can create variation in inter-individual differences in behavior and development, creating heterogeneity (Lerner et al., 2010). Variables that go beyond culture, race, and ethnicities such as national origin, migration patterns and time, social support, legal context, education, resource accessibility, and socioeconomic variables impact participation in research (Rodriguez et al., 2006; Cherepakho et al., 2008).

Understanding the motivations to participate in the current study addresses this need through a qualitative approach to address the following research questions.

Hypotheses and Expected Results

Hypotheses for this project are mainly exploratory, as literature has inconclusive and limited results regarding the motivations of minority groups, such as Latinos/Hispanics and Black/African Americans in AD prevention clinical research.

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- Experience with someone who had Dementia or AD or helping society will be the highest motivator regardless of ethnicity or race, highlighting extrinsic motivation.
- The second highest motivator will be concern or control over illness, as frequently reported in the literature highlighting an extrinsic identified motivation.
- Latinos/Hispanics and Black/African Americans might have higher personal referral numbers or higher desire to help the community over individual interests, highlighting the importance of extrinsic introjected motivation in collectivistic cultures.

Methods

Participants

The participants in the study were 3,786 older adults 65 years and older ($M = 72.83$, $SD = 5.07$) without cognitive impairment. Demographics (**See Table 1**) indicated the sample had more women (71%) compared to men. Furthermore, 32% of the sample had between 16 to 17 years of education (i.e., Bachelor's and/or some professional education after college graduation).

Participants consented and were screened for the Preventing Alzheimer's with Cognitive Training (PACT) study between June 2019 and February 2022 at the University of North Florida ($n = 294$), the University of South Florida ($n = 1,766$), the University of Florida ($n = 119$), Clemson University ($n = 214$), and Duke University ($n = 223$; **See Table 2**). The PACT study is a double-blinded clinical research trial that follows participants across three years. The study aims to evaluate whether computerized training exercises, also called "brain games," lower the risk of cognitive impairment or Dementia for older adults. The total sample includes participants who completed the initial eligibility assessment for participation in the study. The PACT study is registered at Clinicaltrials.gov NCT0384831, supported by the National Institute of Aging (R56

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AG058234 and AG070349), and is overseen by a centralized review board [Western Institutional Review Board (WIRB)]

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Table 1

Demographics for the total sample

		Total		Black/African American		Hispanic		White	
		n= 2,616		n= 211		n= 157		n= 2,304	
Gender									
	Female	1860	71.1%	171	81.0%	115	73.2%	1622	70.4%
	Male	756	28.9%	40	19.0%	42	26.8%	682	26.6%
Education									
	M	16.39	-	15.95	-	16.00	-	16.43	-
	SD	2.263	-	2.313	-	2.336	-	2.250	-
	Skewness	-.359	-	-.237	-	-.028	-	-.371	-
	Kurtosis	-.695	-	-.514	-	-.974	-	-.701	-
	9 th - 12 th	119	4.5%	11	5.2%	9	5.7%	100	4.3%
	13 th – 15 th	540	20.6%	58	27.6%	43	27.4%	462	20.1%
	16 th - 17 th	847	32.4%	66	31.4%	52	33.1%	753	32.7%
	Master’s Degree	835	31.9%	59	28.1%	37	23.6%	742	32.2%
	Doctorate Degree	274	10.5%	16	7.6%	16	10.2%	247	10.7%

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Age

M	72.83	-	71.49	-	71.82	-	72.97	-
SD	5.07	-	4.544	-	4.932	-	5.12	-
Skewness	.721	-	.985	-	.725	-	.699	-
Kurtosis	.225	-	.776	-	.065	-	.203	-

Note. 126 Hispanics reported being White and 5 Hispanics reported being Black. The race variable had 101 cases missing.

Table 2

Participants by PACT University Site

	N= 2,616	%
USF Travel	42	1.6%
USF Tampa	799	30.5%
USF Lakeland	383	14.6%
USF St. Petersburg	542	20.7%
Duke	223	8.5%
UF	119	4.5%
Clemson	214	8.2%
UNF	294	11.2%

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Measures

The PACT study involves at least three in person appointments across 3 years. The first in-person appointment is scheduled after a 30-minute telephone prescreening interview. If participants qualify and are enrolled during the first appointment, they complete the second appointment within a month and a third one three years later. The first appointment involves an explanation of the study, detailed cognitive testing, and the completion of questionnaires including the motivation questionnaire. The motivation questionnaire, which is completed after the cognitive test but before eligibility is confirmed, is related to motivation to engage in the study and includes four questions: "*What made you interested in participating in PACT?*", "*What do you hope to get out of your participation in PACT?*", "*What can you do if you get discouraged or frustrated during your training sessions?*", "*What are three things that your trainer can do to motivate you if you get discouraged or frustrated during your training sessions, or if you find it difficult to complete your weekly sessions?*". Before the completion of the motivation questionnaire participants are encouraged by the study staff to refer to a pamphlet that lists the possible benefits of cognitive training (**Appendix A**).

Procedures

A team of three PACT staff members followed thematic analysis guidelines by Braun & Clarke, (2006) to analyze secondary data. The analysis of participants' responses to the motivation questionnaire followed six stages, (a) familiarization of data, (b) code generalization, (c) organization of codes into themes, (d) reviewal of data to ensure completeness, (e) categorization and (f) labeling of themes. Researchers scored the first 300 answers for each question twice and reached 80% interrater agreement.

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The major themes were identified and organized into a codebook with categories, definitions, and examples. Further categorization of the codebook motivators was based on the Self-Determination Theoretical model by Deci & Ryan (2000) (**Appendix B**). Only two questions from the motivation questionnaire that addressed personal motivations for participating in the PACT study were included in the analysis. Six major themes were found in response to the first question, “*What made you interested in participating in PACT?*”. The extrinsic identified motivations (i.e., activity is considered meaningful and valuable) included *concern about brain health and aging, general (or Dementia specific) research interest, and direct experience with the disease*. The intrinsic motivations (i.e., enjoyment, fun, learning) included *altruism and general personal interest*. The extrinsic introjected (i.e., ego involvement and reputational gains) motivation included *referrals*. Five major themes were also found in response to the second question, “*What do you hope to get out of your participation in PACT?*”. The extrinsic identified motivation contained themes including the *prevention of Dementia or cognitive decline and personal brain health*. Intrinsic motivation included *general personal benefits*, while extrinsic introjected motivation included *benefits to research and others*. A fifth uncategorized theme was created to group themes that did not fit within other categories.

Data Analysis Plan

For analysis purposes frequency statistics of motivational themes were calculated for the entire sample. Due to the limitation of sample size for the minority groups and significant differences in demographic variables, researchers used case-control matching. Case-control matching is a common method for an efficient analysis of low-incidence populations and to balance covariates between targeted groups, including historically marginalized groups (Niven et al., 2012; Franklin, 2015; Rosenbaum & Rubin, 1983; Flores & Park, 2013). Prior to conducting

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chi-squared categorical analysis for the motivational themes based on race and ethnicity, researchers used case matching between the Black/African American (**See Table 3**), Latino/Hispanic (**See Table 4**), Non-Hispanic and White/Caucasian subsamples to match gender, education, and age between the groups. Parametric for each control-case matching were the following: matched exact gender, education a maximum of one category difference (i.e., 9th to 12th, 13th to 15th, Bachelor, Master and Doctorate) and age a maximum of a seven-year difference between cases.

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Table 3

Demographics for matched comparison by race

	Total		African American/Black		White/Caucasian	
	n= 420		n= 210	50%	n=210	50%
Ethnicity						
Latino	5	98.8%	5	2.4%	0	-
Non-Latino	415	1.2%	205	97.6%	210	100%
Gender						
Female	342	81.4%	171	81.4%	171	81.4%
Male	78	18.6%	39	18.6%	39	18.6%
Education						
M	15.75	-	15.99	-	15.51	-
SD	2.313	-	2.522	-	2.364	-
Skewness	.253	-	-.096	-	.595	-
Kurtosis	-.910	-	-.976	-	-.610	-
9 th - 12 th	15	3.6%	11	5.2%	4	1.9%
13 th - 15 th	147	35.0%	58	21.6%	89	42.4%
16 th - 17 th	147	35.0%	66	31.4%	81	38.6%
Master's	66	15.7%	59	28.1%	7	3.3%

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	Doctorate	45	10.7%	16	7.6%	29	13.8%
Age	M	71.26	-	71.51	-	71.01	-
	SD	4.478	-	4.539	-	4.413	-
	Skewness	.863	-	.984	-	.736	-
	Kurtosis	.742	-	.778	-	.679	-

**Note. There were significant differences based on participants' ethnicity by race (p=.033*), and education by race (p= .0.04*). There were no significant differences between participants' gender by race(p=.10), and age by race (p=.253).*

Table 4

Demographics for matched comparison by ethnicity

	Total		Yes Latino/Hispanic		No Latino/Hispanic		
	n= 315		n=157		n=158		
			49.8%		50.2%		
Race	White	256	81.3%	126	80.2%	130	82.3%
	Black	10	3.2%	5	3.2%	5	3.2%
	Other	24	7.6%	12	7.6%	12	7.6%
	Missing	25	7.9%	-	-	-	-

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Gender

Female	232	73.7%	115	73.2%	117	74.1%
Male	83	26.3%	42	26.7%	41	25.9%

Education

M	15.86	-	16.00	-	15.73	-
SD	2.516	-	2.336	-	2.679	-
Skewness	.209	-	-.028	-	.403	-
Kurtosis	-1.152	-	-.974	-	-1.229	-
9 th - 12 th	15	4.8%	9	5.7%	6	3.8%
13 th - 15 th	110	34.9%	43	27.4%	67	42.4%
16 th - 17 th	89	28.3%	52	33.1%	37	23.4%
Master's Degree	53	16.8%	37	23.6%	16	10.1%
Doctorate	46	14.6%	16	10.2%	30	19.0%

Age

M	71.48	-	71.82	-	71.13	-
SD	5.140	-	4.932	-	5.332	-
Skewness	.800	-	.725	-	.900	-
Kurtosis	.231	-	.065	-	.446	-

**Note: There were significant differences between participants education based on ethnicity (p=.001)*

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Results

Frequencies of motivational themes indicate the three most cited reasons for participating in the PACT study were: direct experience with the disease (ex: “Family history of memory loss, mother and her younger siblings were all diagnosed with AD.”), concern about brain health (ex: “Preventing cognitive decline or improvement to their memory due to aging”), and general interest in research (ex: “Opportunity to find methods to improve the quality of mental life for the aging population through a research study”). The three most endorsed motivations related to what people hope to get out of their participation were: personal brain health, general personal benefit, and benefit to research and others (**See Table 5**).

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Table 5

Frequencies for motivational themes by race/ethnicity

	Total sample		Hispanic		Black/African Americans	
Q1: What made you interested in the PACT study	n= 2,616		n=157		n=211	
	n	%	n	%	n	%
Direct Experience with the Disease	697	26.6	42	26.8	55	28
Subtheme						
Immediate	470	67.43	27	87.1	35	83.3
Extended	76	10.90	4	12.9	7	16.7
Concern about Brain Health and Aging	645	24.7	46	29.3	59	28
General Personal Interest	465	17.8	32	20.4	43	20.4
General Research Interest	522	20	21	13.4	36	17.1
Dementia Research	395	75.97	20	100	24	100
Referrals	145	5.5	7	4.5	6	2.8
Subtheme						
Spouse	31	20.83	2	25	2	33.3
Family/Friends	47	32.64	4	50	2	33.3
Professional Organization	83	57.64	2	25	2	33.3
Altruism	142	5.4	9	5.7	8	3.8

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Q2: What do you hope to get out of your participation	n = 2,468		n=157		n=211	
	n	%	n	%	n	%
Personal Brain Health	784	31.76	62	42.5	73	34.60
Subtheme						
Improve	552	70.41	42	66.67	46	63.01
Maintain	136	17.35	12	19.05	15	20.54
General Personal Benefit	645	26.13	36	26.7	63	29.9
Benefit to research and others	520	21.07	21	14.4	29	13.7
Prevent Dementia or Cognitive Decline	451	18.27	26	17.8	39	18.5
Uncategorized	68	2.75	1	0.7	7	3.3

Note: Subthemes percentages were calculated based on the number of participants who reported the theme. Sample size for question 2 had 148 cases less than sample size for question 1.

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Motivational differences for Latinos/Hispanics.

Chi-squared tests of independence were conducted to determine if motivational themes differed based on ethnicity (**Table 6**). 157 Latino/Hispanic respondents and 158 Non-Latinos/Hispanics matched control cases were included in the analyses. For the first item, *'What made you interested in PACT?'*, Latinos/Hispanic were more likely to report concerns about brain health and aging as a motivation (59.7%) compared to Non-Latinos/Hispanics/ (40.3%; $\chi^2 = 3.99$, $p < .05$, $\phi = .11$). On the other hand, Latinos/Hispanic were less likely to report general research interest as a motivation (38.2%) compared to Non-Latinos/Hispanics (61.8%; $\chi^2 = 3.62$, $p = .05$, $\phi = -.11$). Other reported motivational themes and subthemes (i.e., direct experience with the disease, general personal interest, altruism and referral) did not differ significantly across ethnicity.

For the second item, *'What do you hope to get out of your participation in PACT?'*, Latinos/Hispanic were more likely to report improving their personal brain health as a motivation (60.9%) compared to Non-Latinos/Hispanics (39.1%; $\chi^2 = 4.30$, $p < .05$, $\phi = .12$). In addition, chi-squared analysis for uncategorized motivations (i.e., *reported motivation that did not fit into any of the codebook motivational themes*) was significant ($\chi^2 = 5.56$, $p < .05$, $\phi = -.13$), but not valid since the value of the cell for Latinos/Hispanics was less than five (Bewick et al., 2003). Other reported motivational themes and subthemes (i.e., preventing Dementia or cognitive decline, general personal benefit, general personal interest, and benefit to research and others) did not differ significantly across ethnicity.

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Table 6

Chi-squares of motivational themes based on ethnicity

		Non-Latino/Hispanic		Latino/ Hispanic		
Q1: What made you interested in the PACT study?						
Motivational themes	n	n	%	n	%	χ^2
Direct Experience with the Disease	79	37	46.80	42	53.16	.495
Subtheme						.263
Immediate	63	36	57.14	27	42.86	-
Extended	6	2	33.33	4	66.67	-
Concern about Brain Health and Aging	77	31	40.30	46	59.70	.046*
General Personal Interest	73	41	56.20	32	43.80	.242
General Research Interest	55	34	61.80	21	38.20	.057*
Dementia Research	43	20	46.51	23	53.49	.607
Referrals	16	9	56.25	7	43.75	.617
Subtheme						.713
Spouse	3	1	33.33	2	66.63	-
Family/Friends	10	6	60	4	40	-

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	Professional Organization	4	2	50	2	50	-
Altruism		15	6	40	9	60	.420
Q2: What do you hope to get out of your participation							
Motivational themes		n	n	%	n	%	χ^2
Personal Brain Health		113	50	44.24	63	55.75	.117
	Improve	69	27	39.13	42	60.87	.038*
	Maintain	26	13	50	13	50	.987
General Personal Benefit		86	44	51.16	42	48.84	.827
Benefit to research and others		48	25	52.08	23	47.92	.772
Prevent Dementia or Cognitive Decline		59	31	52.54	28	47.45	.685
Uncategorized		9	8	88.89	1	11.11	.018*

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Motivational differences for Black/African Americans.

Chi-squared analyses of motivational themes across racial groups, included 210 Black/African Americans respondents and 209 White/Caucasian matched control cases (**Table 7**). For the first item, "*What made you interested in PACT?*", Black/African Americans were more likely to report concerns about brain health as a motivation (59.6%) compared to White/Caucasians (40%; $\chi^2 = 4.66$, $p < .05$, $\phi = .12$). Other reported motivational themes and subthemes (i.e., direct experience with the disease, general personal interest, altruism, and referral) did not differ significantly based on race. There were no significant motivational differences across racial groups for the second item, "*What do you hope to get out of your participation in PACT?*".

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Table 7

Chi-squares of motivational themes based on race

		White		Black/African Americans		
Q1: What made you interested in the PACT study?						
Motivational themes	n	n	%	n	%	χ^2
Direct Experience with the Disease	123	64	52.03	59	47.96	.570
Subtheme						.364
Immediate	79	44	55.70	35	44.30	-
Extended	12	5	41.67	7	58.33	-
Concern about Brain Health and Aging	99	40	40	59	59.60	.031*
General Personal Interest	80	37	46.25	43	53.75	.470
General Research Interest	75	40	53.33	35	46.67	.509
Dementia Research	53	28	52.83	25	47.17	.607
Referrals	18	12	66.66	6	33.33	.145
Subtheme						.713
Spouse	4	2	50	2	50	-
Family/Friends	7	5	71.43	2	28.57	-
Professional Organization	7	5	71.43	2	28.57	-

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Altruism	24	16	67	8	33.33	.090
Q2: What do you hope to get out of your participation						
Motivational themes	n	n	%	n	%	χ^2
Personal Brain Health	145	72	49.65	73	50.34	.946
Improve	95	49	51.58	46	48.42	.726
Maintain	22	7	31.82	15	68.18	.080
General Personal Benefit	112	49	43.75	63	56.25	.130
Benefit to research and others	67	38	56.71	29	43.28	.222
Prevent Dementia or Cognitive Decline	85	47	55.29	38	44.70	.264
Uncategorized	10	3	30	7	70	.203

Discussion

We identified motivational themes for participating in research for cognitively healthy individuals aged 65 or older in the Preventing Alzheimer's with Cognitive Training (PACT) study. For this study, we had two goals: 1) to identify and examine motivational themes for participating in research and 2) to compare how motivation to participate may differ across race/ethnicity. In doing so, we hope to provide insight into decision-making processes related to research participation and increase recruitment of historically underrepresented and marginalized groups.

Our first study goal had two hypotheses. Our first hypothesis was supported as the most common motivational theme indicated that people participated in the study because of their extrinsic identified motivation (i.e., activity is considered meaningful and valuable) reflected by *direct experience with the disease* (26.6%). This finding is consistent with Coley and colleagues (2021) who found that personal experience and perceptions of AD were associated with a greater chance to participate in a 3-year multidomain lifestyle intervention trial to prevent cognitive decline for individuals aged ≥ 70 .

Our second hypothesis predicted the second most reported motivator of the study would be participants reporting to have control or concern about health. Results indicated *concern about brain health and aging* (25%) was the second most reported motivational theme for why people participated in the study. In addition, the most reported item people hoped to get out of their participation was *personal brain health* (31.76%). Both results indicate that brain health and aging as a motivator reflects extrinsic identified motivation (i.e., activity is considered

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meaningful and valuable). Results are parallel with Smith and colleagues (2015) who found that about 52.3% of their sample reported being motivated to take action to improve their mental health, including mental activity (20%).

The second goal of the study was to investigate potential differences of motivational themes based on race and ethnicity to help increase the representation of ethnic and racial historically marginalized groups, such as the African American/Black and Latino/Hispanic community. Though we did not find significant differences supporting our initial hypothesis for referrals (i.e., *interest stems from someone in their life / social circle referring them to the study*), across race and ethnicity, we did find that for Latinos/Hispanics, general research interest was lower (38.2%) than for Non-Latinos/Hispanics (61.8%). This difference has been consistently reported in the literature (Nuytemans et al., 2019; Marquez et al., 2022; Karlawish et al., 2010). However, a recent study by Garza et al. (2017) with 1, 264 Latinos/Hispanics reported that 65% participated in medical research, mainly motivated by health benefits, but only 15% were asked to participate. Rather than a lack of research interest in the community, existing structural barriers (e.g., lack of community engagement research practices, unavailability of culturally sensitive educational resources, scientific mistrust, eligibility criteria) is responsible for reducing awareness of AD and related Dementias clinical research opportunities in the community, showcasing the needed effort from researchers and institutions to provide AD information and resources (Massett et al., 2021; Raman et al., 2021).

For both the Latino/Hispanic and Black/African American participants, *concern about brain health and aging* was higher than for White/Caucasians. This result reflects a previous study investigating the motivation typologies of participating in aging research in 472 individuals (3.0% Non-Hispanic Black and 2.5% Hispanic). Results suggested the highest proportion of

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brain health advocates (n=91) were not only non-white (7.7%), but also had lower levels of subjective health compared to other motivational typologies (Carr et al., 2022). A possible explanation for a higher concern about brain health and aging might be due to the higher tendency of ethnic and racial historically marginalized groups to self-report cognitive health status as poor or fair compared to non-Hispanic White/Caucasians (Luo et al., 2015; Jang et al., 2021). On the other hand, racial and ethnic within-group variations in subjective cognitive health and objective cognitive performance are evidence of the influence of the interaction of a variety of determinants of health model and sociodemographic characteristics (Jang et al., 2021). For example, having multiple chronic medical conditions and cultural differences influence the perception of aging and cognitive health (Helman, 2007).

Conclusions and Future Directions

Understanding the motivations to participate in Dementia research and prevention for diverse populations can aid in breaking the cyclical pattern of underrepresentation of historically marginalized groups in research and increase knowledge of how Dementia impacts historically marginalized groups through more personalized and consumer-focused marketing strategies for research (Yancey, 2006). The most common motivational themes for cognitively healthy individuals aged 65 or older participating in the Preventing Alzheimer's with Cognitive Training (PACT) study were *direct experience with the disease* (26.6%), *concern about brain health and aging* (25%), and *personal brain health* (31.7%).

The most common motivational themes in the study reflected extrinsic identified motivation (i.e., activities that are meaningful and essential) suggesting a high level of self-determination and a more internalized motivation and conscious processing in their motivation for participating in the PACT study, regardless of ethnicity or race (Ryan & Deci, 2000). The

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prevalence of concern about cognitive/brain health and aging in motivational themes reflect American society' beliefs around Dementia and cognitive decline. For example, six in ten adults, age 40 and older believe cognitive decline is an inevitable characteristic of aging, and 48% of United States adults believe they will develop Dementia in the future (Mehegan & Rainville, 2021; Global Council of Aging, 2022). The concern of the cognitive decline in society, and modifiable factors accounting for 40% of dementia cases opens a great opportunity to increase participation through awareness of the power of non-pharmacological preventative methods and cognitive health resources that might be available within a research environment, especially for Black/African Americans and Latinos/Hispanics (Coley et al., 2021).

Differences of motivational themes based on race and ethnicity found a small effect, suggesting that Latino/Hispanics and Black/African American had a higher *concern about brain health and aging* compared to White/Caucasians. Social determinants of health, individual characteristics, and cultural perceptions can influence the lower perception of personal cognitive health in Black/African Americans and Latinos/Hispanics (Luo et al., 2015; Jang et al., 2021; Helman, 2007). For example, Black/African Americans and Latinos/Hispanics present more impairment at the time of AD diagnosis because they seek care at later progress stages of the disease due to discrimination experiences, cultural and language barriers, and lack of access to health resources (Cooper et al., 2010; Lines et al., 2014). Furthermore, the existing comorbidity of cardiovascular disease and type 2 diabetes influences Dementia diagnosis in the Latino/Hispanic and Black/African American groups because it increases the risk of cognitive impairment and influences the report of frequency and severity of symptoms (Glymour & Manly, 2011; Mayeda et al., 2014). A second finding in this study suggests Latinos/Hispanics had a lower motivation for *general research interest* compared to White/Caucasians. Although

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previously reported in the literature, systematic barriers and a lack of opportunities for research in the community can contribute to a lower research interest (Masset et al., 2021; Nuytemans et al., 2019; Marquez et al., 2022; Karlawish et al., 2010; Garza et al., 2017).

Future research should investigate the intersectionality of the found motivations (e.g., *direct experience with Dementia, personal brain health, concern about cognitive health and aging*), or incorporate conditional indirect effects (e.g., health/disease perception) *in the* decision process in research participation. For example, people who had personal experiences with AD were more likely to participate in research due to a greater fear of AD or AD family history, initiate behaviors related to brain health improvement, and interest in receiving health education about the disease (Coley et al., 2021). Researchers need to investigate the interaction of other individual and context variables beyond race and ethnicity such as age, gender, education, and perceptions of health which might influence historically marginalized groups' motivational themes for participating in research (Lang et al., 2013; Nuytemans et al., 2019; Perreira et al., 2020). Future research should investigate the effectiveness of marketing and recruitment materials that incorporate the different motivational themes found in the study. In addition, more attention should be placed on socioemotional selectivity theory framework which presents the perception of the remaining time as we age and how it increases the engagement of activities that are emotionally meaningful (Carstensen, 1992b).

Strengths & Limitations

The current study has some limitations, including the generalizability to other geographic locations beyond individuals in the southeast region of the United States, which is important as historical period and geographical location can influence the social categorization of race and ethnicity (APA, 2019). Sample limitations include the lack of inclusion of Black/African

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American and Latino/Hispanic subgroups due to the small subgroup sample sizes, which fails to consider intergroup dynamics and contributes to oversimplification of these groups (Leong & Cheung, 2010; Canevelli et al., 2019). In addition, our sample's education had a mean of 16 years indicating participants were college-level educated. Our comparison groups differ in their education after matched-case analysis, which limits our results, as education can influence subjective cognitive decline and motivations to participate in research in historically marginalized groups (Röhr et al., 2020; Lang et al., 2013; Nuytemans et al., 2019). Future efforts need to consider intergroup dynamics and more strict matched-comparison education parametric.

In addition to sample constraints, participants were provided with a pamphlet describing the cognitive benefits of cognitive training before completing the motivation questionnaire, which might have contributed to positive attitudes toward the study and influenced reported motivators (Chang, 2007). Statistical analysis findings were limited as Post Hoc power analysis in G*Power for chi-squares measuring differences of motivators based on ethnicity and race was slightly underpowered around 50-62% power and had a small effect ($\phi = 0.11$). Furthermore, the comparison analysis used White/Caucasians as the reference group which might contribute to the “Whiteness/Westernized” standard and race deficit when addressing health disparities (Purnell et al., 2016). On the other hand, the study has some strengths, including the sample size allowed saturation for thematic analysis for the motivational themes. In addition, the motivation questionnaire provided a multidimensional perspective into why people participate in research and what they hope to get out of their participation addressing motivation in a more holistic approach to increase the representation of Black/African Americans and Latinos/Hispanics in clinical research.

Considerations for Diversity, Equity and Discrimination:

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The current study contributed to the known motivations to participate in a clinical AD prevention study in underrepresented ethnic and racial groups to increase future recruitment strategies for historically marginalized groups in clinical trials. However, our findings are limited as existing systematic barriers for historically marginalized groups that directly and indirectly impact the decision-making process when participating in clinical trials were not investigated. For example, the high discrimination in health care for Black/African American (50%) and Hispanic/Latino (33%) communities contribute to the existing medical mistrust in research (Alzheimer's Dementia Association, 2021).

Methodological problems related to clinical trials can contribute to underrepresentation of Black/African Americans and Latinos/Hispanics in clinical trials (Manly & Glymour, 2021; Raman et al., 2021). Researchers consistently fail to report race and ethnicity in pharmaceutical clinical trial findings. Despite having 19 Black/African Americans, and 1 Hispanic in their sample, the US Food and Drug Administration (FDA) approved an AD treatment known as Aducanumab (Manly & Glymour, 2021). In addition, health disparities are not considered in eligibility criteria. For example, Black (30.7%), Hispanics (26.1%) and Asian (26.8%) participants are less likely to be eligible after screening Visit 1 due to cognitive inclusion criteria compared to White/Caucasians (16.2%; Raman et al., 2021).

The first step to address the true nature of health disparities in AD for historically marginalized groups is going to require purposeful effort from researchers and institutions in including diverse staff, partnership with community organizations and incorporating methodology that is culturally sensitive (Heller et al., 2014; Yancey, 2006). AD research should incorporate an intersectionality framework as gender, race and ethnicity, class and sexuality are simultaneous complex social categories that influence the interactions we have at a macro and

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micro level throughout development (Wilkins et al., 2020; Bronfenbrenner & Morris, 2006; Cole, 2009; Crenshaw, 2008).

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