

EPIDEMIOLOGY

Impact of Knowledge About Alzheimer's Disease on Interest in Participation in Biomarker Research

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Abstract

Background: Previous studies suggest limited knowledge about Alzheimer's Disease (AD) is a barrier to underrepresented group participation in AD research. Connections between knowledge of AD and factors like social determinants of health or confidence in biomarker research have not been carefully examined. We hypothesized perceived knowledge about AD would be associated with research hesitancy independent of sociodemographics and trust of researchers.

Method: The AD-REACH study surveyed 399 research-naïve non-Hispanic Black and white adults 55 years and older living in Indianapolis, Indiana. Participants reported perceived knowledge of AD on a 5-point scale (5 = "I know what [AD] is, what causes it, and how to manage and prevent it," 1 = "I know nothing at all"). Knowledge was dichotomized into higher (≥ 3) and lower (< 3) levels. Demographics were compared using chi-squared tests and t-tests. Ordinal logistic regression models examined the association between perceived knowledge about AD and outcome variables (e.g., hesitancy towards research participation) and were adjusted for sociodemographics and very high trust of researchers.

Result: Those who reported being Black, male, from a higher Area Deprivation Index, or having less than 16 years of education had lower perceived knowledge about AD (Table 1). Trust of researchers was not associated with perceived knowledge. Those reporting lower AD knowledge described more hesitancy to participate in biomarker research (53.0% vs 72.7%, OR 2.50, 95% CI 4.35-1.39, $p = 0.002$) and blood draw (62.3% vs 80.9%, OR 2.17, 95% CI 4.00-1.19, $p = 0.012$) but not neuroimaging procedures (Table 2). Those with lower perceived knowledge of AD were more likely to need additional

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information to make decision about whether to participate in research (58.1% vs 29.9%, OR 3.70, 95% CI 9.09-1.49, $p = 0.005$) (Table 3).

Conclusion: Populations with health disparities report lower knowledge of AD, and lower perceived knowledge is associated with research hesitancy, especially for biomarker procedures. Perceived AD knowledge is also independent from trust, suggesting the feasibility of a two-pronged intervention to foster diverse participation in AD biomarker research. Future studies will need to confirm these findings in other cohorts and examine how culturally tailored strategies to increase AD knowledge may reduce research hesitancy among underrepresented groups.

Table 1: Demographics and Trust of Researchers in Those Who Do and Do Not Know What AD Is

Demographics		Does Not Know What AD Is N = 69	Knows What AD Is N = 330
Age	55-64 yrs	40.6 (28)	39.4 (130)
	≥ 65 yrs	59.4 (41)	60.6 (200)
Black		89.9* (62)*	59.4 (196)
Female		37.7* (26)*	60.3 (199)
Education	<16 yrs	78.3* (54)*	58.5 (193)
	≥16 yrs	21.7 (15)	41.5 (137)
Married/Long-time Partner		44.9 (31)	51.5 (170)
ADI		71.01* (25)*	64.49 (25)
Very high trust of researchers		63.8 (44)	72.4 (239)

ADI = Area Deprivation Index. All dichotomous variables are described as % (N). The continuous variable ADI is described as mean (SD).

$P < 0.05$ as per chi-squared tests for dichotomous variables and t-tests for continuous variables.

Table 2: Association between Knowledge of AD and Hesitancy to Participate in AD Procedures

Hesitancy of AD Research Procedures	OR (95% CI)	p-value
General interest in AD biomarker study	2.50 (1.39-4.35)	0.002*
Interest in blood draw for genetics	2.17 (1.19-4.00)	0.012*
Interest in brain MRI	0.87 (1.25-1.89)	0.652
Interest in PET scan	1.20 (0.69-2.08)	0.504

OR = odds ratio. CI = confidence intervals.

Ordinal logistic regression model examined knowledge of AD and hesitancy to participate in AD biomarker procedures. Model is adjusted for race, age, gender, college, ADI, and trust of researchers. Cumulative OR and 95% CI are presented.

Knowledge of AD was measured as a dichotomous, independent variable. The outcome variable was defined as the level of hesitancy about participating in the AD biomarker study or individual procedure; level of hesitancy was defined as "yes" to being interested as the lowest level of hesitancy, "unsure" to being interested as medium level of hesitancy, and "no" to being interested as the highest level of hesitancy. Higher OR > 1 indicate those with lower knowledge of AD have higher level of hesitancy to participate in AD procedures.

Table 3: Association between Knowledge of AD and Perception of Barriers to Research Participation

Barriers to AD Research Participation	OR (95% CI)	p-value
I do not know enough about Alzheimer's disease to decide about participating in a research study	3.70 (1.49-9.09)	0.005*
I will not make any difference by participating in a research study	1.89 (0.65-5.56)	0.246
I worry that the study staff/researchers will use my information without my permission	1.13 (0.43-2.94)	0.796
I worry about what they may find in my brain or test results	1.14 (0.14-1.15)	0.091
I worry about the risks of the study	0.73 (0.30-1.75)	0.485
I am not interested in Alzheimer's disease research	0.70 (0.24-2.04)	0.516
I would consider participating in a study now, but I need more information	1.69 (0.71-4.00)	0.228

OR = odds ratio. CI = confidence intervals.

Ordinal logistic regression model examined knowledge of AD and hesitancy to participate in AD biomarker procedures. Model is adjusted for race, age, gender, college, ADI, and trust of researchers. Cumulative OR and 95% CI are presented.

Knowledge of AD was measured as a dichotomous, independent variable. The outcome variable was defined as the level of agreement about whether the following statement was a barrier (This is a reason for me, This is not a reason for me, unsure). Higher OR > 1 indicate those with lower knowledge of AD have higher level of agreement with the barrier.