Retention of American Indian and Alaskan Native Patients in Alzheimer's Disease Research

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Motivation:

➤ American Indian and Alaskan Natives (AI/AN) and other minorities bear a disproportionate burden in ADRD.[1]
➤ Minorities are under-enrolled in ADRD research[2] and Black participants have lower rates of retention in studies.[3]
➤ AI/AN populations are understudied in all settings, including study retention.[4]
➤ We aimed to characterize the retention rates of AI/AN study participants.

Methods:

❖ We used the Uniform Data Set from National Alzheimer's Coordinating Center.
❖ Patients were excluded if their designation was for "initial visit only".
❖ Dropout = a patient's last visit occurring before May 17, 2020 and having no recorded death within 18 months of the visit date.
❖ Time-to-dropout = number of visits (years) until participant dropout.
❖ Hypothesis: AI/AN patients have earlier attrition than NH White subjects.
❖ We analyzed time-to-dropout with the continuation ratio model.
❖ *A priori* adjustment covariates: baseline age, sex, education level, and baseline cognitive status.
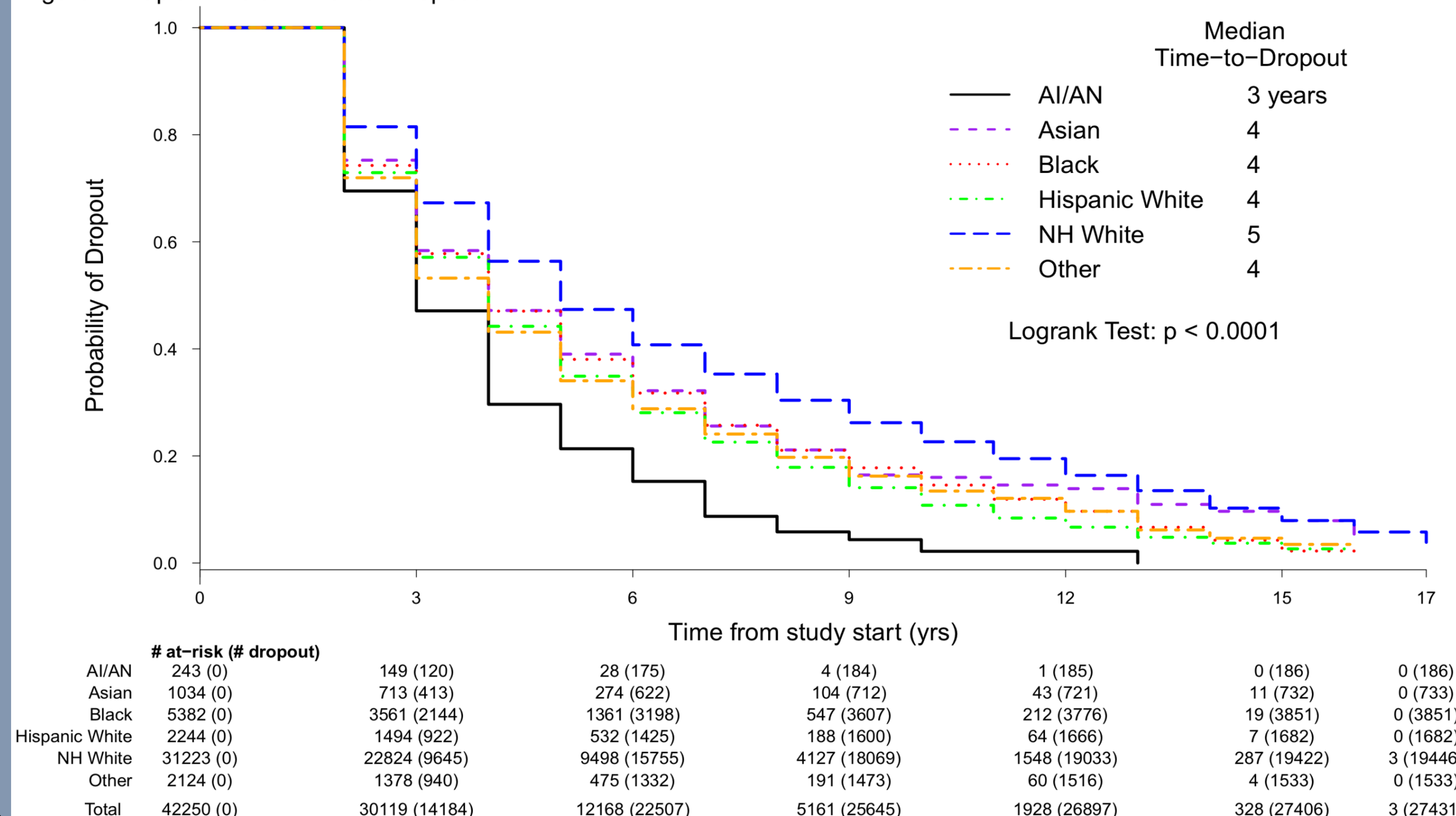
References:

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4 *Tribal Nursing Homes: Best Practices for Patients with Dementia and Alzheimer's Disease.* Department of Health and Human Services, Centers for Medicare and Medicaid Services, 2017.
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Table 1: Descriptive Statistics for NIH Definition of Race/Ethnicity

Characteristics	AI/AN N = 276 (0.6%)	Asian N = 1,161 (2.6%)	Black N = 5,697 (12.7%)	Hispanic White N = 2,378 (5.3%)	Non-Hispanic White N = 32,884 (73.5%)	Other N = 2,317 (5.2%)
Baseline Age	68.01 (10.63)	70.37 (10.29)	71.88 (8.99)	71.02 (10.11)	71.69 (10.68)	69.98 (10.53)
Binary Sex						
Female	178 (64.5%)	678 (58.4%)	4,088 (71.8%)	1,552 (65.3%)	17,511 (53.3%)	1,546 (66.7%)
Male	98 (35.5%)	483 (41.6%)	1,609 (28.2%)	826 (34.7%)	15,373 (46.7%)	771 (33.3%)
Patient Education						
< High school diploma	61 (22.1%)	88 (7.6%)	829 (14.6%)	792 (33.3%)	970 (2.9%)	649 (28%)
High school diploma/GED	105 (38%)	140 (12.1%)	1,395 (24.5%)	474 (19.9%)	5,540 (16.8%)	425 (18.3%)
Some College	54 (19.6%)	141 (12.1%)	1,352 (23.7%)	389 (16.4%)	5,673 (17.3%)	408 (17.6%)
4 Year Degree	28 (10.1%)	317 (27.3%)	851 (14.9%)	302 (12.7%)	8,377 (25.5%)	360 (15.5%)
>4 Year Degree	25 (9.1%)	456 (39.3%)	1,234 (21.7%)	402 (16.9%)	12,082 (36.7%)	437 (18.9%)
Baseline Cognitive Status						
Normal Cognition	104 (37.7%)	487 (41.9%)	2,533 (44.5%)	830 (34.9%)	12,839 (39%)	812 (35%)
Impaired-not MCI	14 (5.1%)	51 (4.4%)	363 (6.4%)	133 (5.6%)	1,260 (3.8%)	168 (7.3%)
MCI	57 (20.7%)	304 (26.2%)	1,313 (23%)	608 (25.6%)	6,977 (21.2%)	497 (21.5%)
Dementia	101 (36.6%)	319 (27.5%)	1,488 (26.1%)	807 (33.9%)	11,808 (35.9%)	840 (36.3%)

Figure 1: Kaplan–Meier Time-to-Dropout

	Median Time–to–Dropout
AI/AN	3 years
Asian	4
Black	4
Hispanic White	4
NH White	5
Other	4

Logrank Test: p < 0.0001

at–risk (# dropout)

AI/AN	243 (0)	149 (120)	28 (175)	4 (184)	1 (185)	0 (186)	0 (186)
Asian	1034 (0)	713 (413)	274 (622)	104 (712)	43 (721)	11 (732)	0 (733)
Black	5382 (0)	3561 (2144)	1361 (3198)	547 (3607)	212 (3776)	19 (3851)	0 (3851)
Hispanic White	2244 (0)	1494 (922)	532 (1425)	188 (1600)	64 (1666)	7 (1682)	0 (1682)
NH White	31223 (0)	22824 (9645)	9498 (15755)	4127 (18069)	1548 (19033)	287 (19422)	3 (19446)
Other	2124 (0)	1378 (940)	475 (1332)	191 (1473)	60 (1516)	4 (1533)	0 (1533)
Total	42250 (0)	30119 (14184)	12168 (22507)	5161 (25645)	1928 (26897)	328 (27406)	3 (27431)

Results:

✓ On average, AI/AN patients are younger compared with the other race/ethnic groups and comprise just 0.6% of the sample (1.1% of US population[5]).
✓ AI/AN patients tend to have fewer visits than other race/ethnic groups.
✓ AI/AN patients dropped out earlier than NH White patients (Table 2).

Table 2: Time-to-Dropout Results

Covariate	Adjusted Odds Ratio (95% CI) (N = 41,918, 240 AI/AN) (N Dropout = 27,197, 183 AIAN)
Race/Ethnicity	
NH White	Referent
AI/AN	1.68 (1.42, 1.98) **
Asian	1.27 (1.17, 1.38) **
Black	1.29 (1.24, 1.34) **
Hispanic White	1.27 (1.20, 1.34) **
Other	1.24 (1.16, 1.31) **

Discussion:

➤ We observed earlier attrition of AI/AN patients compared with non-Hispanic White patients.
➤ Longitudinal studies quantifying the burden of ADRD in AI/AN communities may be at risk for bias without adequate retention of AI/AN participants.
➤ Future research should assess potential causes of dropout and interventions to improve retention of AI/AN participants.
➤ Conjecture: Having AI/AN staff involved in research processes (esp. data collection) may help.