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## Barriers To Alzheimer's Disease Clinical Trial Participation in Hawaii's Minority-Majority Population



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**Background:** Alzheimer's disease (AD) is the most common neurodegenerative disorder in the United States and disproportionately burdens minority populations. Yet, clinical AD trials regularly face a shortage of eligible participants numbering in the thousands and this number is set to increase in the next several years. As such, recruitment barriers have been noted as the primary factor negatively impacting AD clinical research progress. While research has been conducted to assess the primary reasons for the lack of clinical trial participation in minority groups, amongst minority populations, Asians and Native Hawaiians are the most understudied. This study explores the barriers to AD clinical trial participation in patients diagnosed with AD or mild cognitive impairment (MCI) in Hawai'i, the state with the largest relative population of Asian and NHPI in U.S.

**Objectives:** Understanding barriers to Alzheimer's Disease (AD) clinical trial participation in underrepresented Asian and Native Hawaiian (NH) patients diagnosed with AD or mild cognitive impairment (MCI) in Hawaii.

**Methods:** Patients and caregivers completed a 15-question telephone survey that assessed demographics, barriers, and improvement methods. Descriptive statistics were performed using Wilcoxon rank-sum test for continuous variables and Fisher's exact test for categorical variables. Incomplete surveys were included for analysis.

**Results:** Forty-nine patients responded (29 AD, 20 MCI). The mean patient age was 77 years, 51% were male, and the mean MMSE score was 23.2. Compared to the clinic population (20.0% Asian, 30.7% NH, 39.7% White), 5.6% Asian, 22% NH, and 32% White patients were in an active trial. More NH and White patients participated in trials than Asian patients. The decision to participate in trials to help others significantly differed by race (91% White, 80% NH, 29% Asian;  $p=0.023$ ), with other reasons being statistically insignificant. Asian (30%) and NH (80%) patients reported the main barrier to participation was a lack of information about trials, with psychosocial conflicts and financial burdens as the least important barrier. Additional trial information given to family members (64% Asian, 88% NH, 62% White) and patients (64% Asian, 88% NH, 46% White) were listed as the most popular trial improvements.

**Conclusions:** Asian and NH patients were less likely to participate in AD trials compared to White patients. A deficiency in information was the primary barrier amongst minority patients. To overcome this barrier, increased outreach and education to patients and their families should be pursued. The results of this study reflect that Asian and NH patients feel they are often lacking information and face logistical obstacles when it comes to AD clinical trial participation. Interestingly, White patients shared comparable barriers indicating that all three groups had similar impediments to involvement potentially indicating problems with how trials are run across all three races. The top two trial improvement methods were consistent across Asian and NH populations (additional information provided to family members and patients), but White patients were equally concerned with financial burdens, transportation logistics, and information provided to family members when considering their second most important trial change. A primary limitation to this study was the small sample size of completed responses, and as such, future research should investigate these barriers in a larger cohort spanning a wider range of time to better generalize results and provide a more complete dataset.