

EPIDEMIOLOGY

Underrepresented minorities in US dementia clinical trials 2010-2020: A systematic review

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Abstract

Background: Though Alzheimer's disease and related dementia (ADRD) risk is higher among Blacks (13.8%) and Hispanics (12.2%) compared to non-Hispanic whites (10.3%), diverse groups are underrepresented in randomized control trials for dementia. This systematic review examined reports of race/ethnicity in RCTs from 2010-2020 and included pharmacological, nutraceutical, nutritional, TMS or other CNS interventions for AD.

Method: A comprehensive search was executed in MEDLINE/Embase of published RCTs on MCI/AD participants from 2010-2020. Using Covidence software, study selection was conducted independently by 10 trained reviewers. Two reviewers independently screened each article for inclusion, abstracted data. Conflicts were resolved by senior authors. 3,281 articles were reviewed, 515 assessed for eligibility, with data extraction conducted on 148; data presented focused on 85 studies conducted in the U.S. Average number and proportion of participants in studies that reported each race/ethnic group were computed.

Result: 49/85 (58%) studies reported race/ethnicity in some way: 15 reported race and ethnicity as separate variables, 10 reported race/ethnicity as one variable (i.e., non-Hispanic Black), 15 did not specify if race and ethnicity were separate variables, and 11 only reported the % of Whites. Of the 49 studies that reported any race/ethnicity information, all 49 reported the number of White participants, who on average constituted 85.4% (range 30-100%) of study samples. In the 35 studies that mentioned Blacks, Blacks constituted an average of 8.6% (range 0-33%) of study samples. In the 16 studies that mentioned Asians, the mean was 6.7% (range 0-47%). Only 3 studies mentioned Native Americans, representing 1% (range .8-1.4%) of study samples. 28 studies reported Latinx's: they accounted for a mean of 13.4% of the samples (range 0-92%).

Conclusion: Despite efforts to improve diverse recruitment, just over half of studies conducted in the U.S. reported race/ethnicity at all, and those that did frequently presented data in a manner that is difficult to interpret (e.g., only % of Whites). Underrep-

resented minorities continue to be grossly underrepresented and/or underreported in dementia clinical trials.