

# Alzheimer's patients with non-spousal caregivers are less likely to participate in clinical trials

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People with Alzheimer's disease are less likely to participate in a clinical trial if they have non-spouse caregivers, according to a study by a team of researchers including the Perelman School of Medicine at the University of Pennsylvania. The new study, published in the December 19th, 2012, issue of *Neurology*, the medical journal of the American Academy of Neurology, demonstrates that additional recruitment and retention strategies may be required to increase enrollment of AD patients with caregivers other than spouses.

Alzheimer's trials - which require both the patient with Alzheimer's and a reliable study partner to enroll together - often struggle to recruit enough patients. In this study, two-thirds of Alzheimer's clinical trial participants were accompanied by their spouse, in contrast to the national average showing that 68 percent of people with Alzheimer's primarily receive care from their children, children-in-law or grandchildren. The study also found that AD participants with a study partner who was neither a spouse nor an [adult child](#) were more likely to drop out before the study completed. In addition, these participants were more likely to suffer a serious adverse event during the trial.

"The majority of Alzheimer's patients are cared for by caregivers who are not their spouses, but we discovered that in Alzheimer's disease clinical trials, most patients' caregivers are their spouses," said senior study author Jason Karlawish, MD, co-director of the Penn Memory

Center and professor of Medicine, [Medical Ethics](#) and [Health Policy](#) in the Perelman School of Medicine at the University of Pennsylvania.

"This result is a call to action. Nonspousal caregivers and the patients they care for represent an untapped opportunity to increase recruitment into Alzheimer's [clinical trials](#) and to assure that the research results reflect the broad community of [patients](#) and their caregivers."

The study also found variations in demographics that may be relevant to clinical trial designs. For example, only five percent of participants across the trial were Hispanic and those with an adult child study partner were twice as likely as those with spouse partners to be Hispanic. In addition, six percent of participants were African-American and those with adult child study partners were nearly three times as likely to be African-American as those with spouse study partners. And, while the ratio of men and women with Alzheimer's disease was similar, the majority of study partners/caregivers were female.

Provided by University of Pennsylvania School of Medicine

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