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Why are spousal caregivers more prevalent than nonspousal caregivers as study partners in AD dementia clinical trials?

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Abstract

Objectives—Most Alzheimer's disease (AD) caregivers are not spouses and yet most AD dementia trials enroll spousal study partners. This study examines the association between caregiver relationship to the patient and willingness to enroll in an AD clinical trial and how caregiver burden and research attitudes modify willingness.

Design—Interviews with 103 AD caregivers who met criteria for ability to serve as a study partner.

Results—54% of caregivers were spouses or domestic partners and the remaining were adult children. Willingness to enroll a patient in a clinical trial was associated with being a spouse (OR = 2.53, p = 0.01), increasing age (OR = 1.39, p = 0.01), and increasing scores on the Research Attitudes Questionnaire (OR = 1.39, p < 0.001). No measures of caregiver burden or patient health were significant predictors of willingness. In multivariate models both research attitudes (OR = 1.37, p < 0.001) and being a spouse, as opposed to an adult child, (OR = 2.06, p = 0.048) were independently associated with willingness to participate.

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Conflicts of Interest
For the remaining authors none were declared.

Author Contributions.
Author Contributions are as follows:
Mark S. Cary was responsible for drafting/revising the manuscript, study concept and design, and statistical analysis.
Jonathan D. Rubright was responsible for drafting/revising the manuscript, study concept and design, and statistical analysis.
Joshua D. Grill was responsible for drafting/revising the manuscript, study concept and design, and statistical analysis.
Jason Karlawish was responsible for drafting/revising the manuscript, study concept and design, statistical analysis, study supervision and coordination, and obtaining funding. The opinions expressed in this article are those of the authors and do not necessarily reflect the views of the American Institute of Certified Public Accountants

Conclusions—Spousal caregivers had both a higher willingness to participate and a more positive attitude toward research. Caregiver burden had no association with willingness to participate. The strongest predictor of willingness was research attitudes.

Keywords

Alzheimer's disease; clinical trial recruitment; caregiver; research attitudes; research ethics

Introduction

The clinical trial is essential to discover better treatments for patients with Alzheimer's disease (AD), but trials often fail to meet enrollment timelines.[1] This failure delays completion, increases costs, and potentially biases results[2] or even makes studies unethical.[3]

One unique barrier to AD dementia trial recruitment is the requirement to enroll two people: a patient and a study partner. The primary caregiver typically fills the role of study partner. Study partners are critical to the decision to enroll,[4, 5] and investigators need them to provide medical history, ensure study compliance, report adverse events, and serve as informant for instruments that measure patient cognitive and functional performance to demonstrate efficacy.[6] Although a majority of AD caregivers are adult children and other nonspousal family members,[7, 8] only 33% of trial study partners are not spouses.[9] Discovering why nonspousal caregivers are underrepresented may be an important insight to promote enrolling them into trials and thereby improving AD dementia clinical trial recruitment.

Studies of willingness to participate in AD research suggest at least two possible reasons for this underrepresentation. Willingness is associated with favorable attitudes about research.[10–12] It is possible that spouses have more favorable attitudes than nonspousal caregivers. A second reason is the time and effort needed to participate in research adds to the work of caregiving, so-called "objective burden," and this may also lead to increased subjective burden. Caregivers with low reports of these burdens of caregiving may be more willing to performing the work of being in research that includes attending frequent hours-long study visits and giving daily medication.

Discovering the influence of attitudes about research and the burdens of caregiving on willingness to participate can assist investigators in designing interventions that might improve willingness to participate. The goal of this study was to use a structured vignette describing a typical 21-month long AD dementia clinical trial to determine whether spousal caregivers are more willing than nonspousal caregivers to enroll a patient with AD dementia in a trial, and whether research attitudes and the burdens of caregiving influence this willingness. To assure the ability to compare study partner types, our sample was evenly divided between spouses/domestic partners and adult children or children-in-law of patients with AD dementia.

Methods

Participants and eligibility criteria

Participants were 108 caregivers of patients with National Institute of Neurological and Communicative Disorders and Stroke – Alzheimer's Disease and Related Disorders Association criteria[13] probable AD dementia who attended the Penn Memory Center, lived within a 1.5 hour driving distance from the Penn Memory Center, and self-identified as the person who: 1) would accompany a relative on visits for a trial and complete study forms, 2) served as a knowledgeable informant for healthcare professionals, and 3) assisted the patient in making decisions. Hence, these caregivers could also serve as study partners.

Patients had probable AD dementia, did not reside in a nursing home, and were independent in ambulation and feeding. A total of 108 patient/study partner dyads participated out of the 124 approached to participate (87% response rate). For our analysis, we deleted the 5 partners who were non-relatives, leaving 103 partners in the analysis. These 5 were deleted because they were not legally authorized to serve as decision makers for informed consent in a clinical trial. More complete details of the study including recruitment and data gathering are reported in a previous paper.[14]

Human subjects protections

All participants provided verbal informed consent for participation in this University of Pennsylvania Institutional Review Board approved study.

Data gathering

A research assistant conducted a face-to-face interview in the participant's home or another convenient location. Participants reviewed a two-page description of a clinical trial testing a hypothetical drug "Alzprotex." The description of the Alzprotex trial, adapted from a clinical trial that was recruiting at the Penn Memory Center, included all the items mandated under the federal "Common Rule" requirement for disclosure in informed consent. It included the study's purpose, sponsor, the possible benefits of the study to both the participant and society, and the study details: a 21-month-long randomized and placebo-controlled clinical trial with 50–50 probability of drug versus placebo, all 10 study visits at the Penn Memory Center, and a 2% risk of cardiac damage. Information on the study partner requirements were that the family member was required at each study visit, participates in interviews to learn how the patient and the family member are doing, and is responsible for transporting and accompanying the patient to and from the study visits and will receive $20 for travel expenses for each visit. They were then asked how likely they would be to participate in a clinical trial with these features on a seven point scale ranging from "definitely would not participate" to "definitely would participate."

Covariates

Participants completed the caregiver and patient demographics (age, years of education, race, ethnicity, gender), overall patient quality of life rating (poor, fair, good, very good, excellent), and patient dementia severity (basic activities of daily living (BADL),[15]

instrumental activities of daily living (IADL),[16] and the brief form of the Neuropsychiatric Inventory Severity subscale (NPI-Q)).[17]

To capture the multi-dimensional nature of caregiver burden, we measured six dimensions: financial burden (*How do finances work out at the end of the month?* Answer choice: some money left over, just enough, not enough to make ends meet), estimated travel time to the Penn Memory Center, caregiver health (overall self-rating: poor, fair, good, very good, or excellent), 15 item Geriatric Depression Scale,[18] a short screen for caregiver burden,[19] and the brief form of the Neuropsychiatric Inventory Distress subscale.[17] The first column of Table 1 displays possible ranges for these measures.

Study partner attitudes about research were measured with the Research Attitudes Questionnaire (RAQ), a 7-item scale that asks respondents a series of Likert questions scored from 1 to 5 about their support for and value of research, with total scores ranging from 7 to 35. This scale has appropriate psychometric properties, with higher scores indicating a more favorable attitude about research.[20] Table 3 lists the items in the scale.

Data analyses

We used Stata version 11 for descriptive statistics, and to conduct ordinal logistic regression to predict the level of willingness to participate from the background variables.[21] We used ordinal logistic regression because the method allows the prediction of the probability of each level of the outcome variable for a given value of a predictor. For modeling, we entered ages as decades (that is, age 63 becomes 6.3). We examined the univariate relationships between each patient and study partner characteristic and willingness to participate. Then we constructed multivariate models to examine the relative contribution of the univariate predictors. We followed five steps: first, we examined a model that included all univariate predictors which had a univariate p-value of 0.15 or less; second, we removed the RAQ from the model to find predictors other than the attitudes toward research; third, we ran a model with the measures of burden by themselves; fourth, after examining the relationships between gender, age, and spousal status, we developed the simplest model with research attitudes and other predictors; fifth, we examined a univariate model of each item in the RAQ to determine which items had the greatest prediction.

Results

Participant characteristics

Table 1 shows that the majority of the 103 study partners were female (69%), non Latino (97%) and white (78%) with at least a few years of post-high school education (15.7 years, SD 2.8). Just over half (54%) were spouses or domestic partners (called “spousal” in this manuscript) and the remaining were adult children. Scores of most measures of burden showed wide ranges, with standard deviations being relatively large compared to the mean scores. The mean score on the RAQ was 27.9 (SD 3.2), with a range from 20 to 35.

As expected, spousal status and study partner age were highly correlated. Spouses were 73.4 (SD 9.7) years old, while the adult children were 50.2 (SD 8.4) years old ($t(101)= -12.9$, $p <$

0.001). Spouse caregivers (45%) were more likely than adult children (15%) to be male ($\chi^2_{(1)} = 10.56$, $p < 0.001$).

Willingness to participate in the clinical trial

The distribution of willingness to participate in the Alzprotex clinical trial was not normal, thus we used ordinal logistic regression to study the associations between the outcome of willingness to participate and patient and study partner characteristics. The distribution was: 14.6% definitely would participate, 20.4% probably, 13.6% possibly, 20.4% might or might not, 2.9% possibly would not, 13.6% probably would not, and 14.6% definitely would not.

Patient and study partner characteristics associated with willingness to participate

Table 2 shows the univariate ordinal logistic regression results for each patient and study partner characteristic. Willingness to participate increased significantly for being a spouse rather than a child (OR = 2.53, p = 0.01), for older study partner age (OR = 1. 39, p = 0.01), and with increasing scores on the RAQ (OR = 1.39, $p < 0.001$). The effect for male study partner, which is also associated with being a spouse, was not statistically significant (OR = 2.01, p = 0.08). No measures of study partner burden or patient health were significant univariate predictors.

The first multivariate model used the RAQ score and six other covariates that met the pre-determined cut-off for inclusion in the model: spousal status, caregiver gender, caregiver age, caregiver health, patient educational levels and the patient's IADL score. Only the RAQ score was statistically significant (OR = 1.35, $p < 0.001$). The second model removed the RAQ score, leaving the remaining six covariates. None of these reached statistical significance. The third model used all six measures of caregiver burden. None of these predictors reached statistical significance.

Because caregiver age and spousal status were highly correlated, we performed a stratified analysis by relationship type. Caregiver age did not predict willingness to participate for adult children (OR = 1.02, p = 0.54) or for spouses (OR = 1.02, p = 0.39). We removed caregiver age from the model, predicting willingness to participate from spousal status, caregiver gender, patient education, caregiver health, and patient IADL. Although none of the predictors were statistically significant, spousal status was close to significance (OR = 1.85, p = 0.13). The fourth model, using only the RAQ score and spousal status, found both the RAQ score (OR = 1.37, $p < 0.001$) and being a spousal as opposed to a child study partner (OR = 2.06, p = 0.048) associated with willingness to participate in the AD clinical trial.

Spousal study partners had a higher mean score on the RAQ (28.5, SD 3.2) than did child study partners (27.1, SD 3.2) ($t_{(101)} = -2.21$, p = 0.03). Given the independent associations between willingness to participate and both relationship to the patient and research attitudes, we found two RAQ items differed between spousal versus adult child study partners. Spouses rated higher levels of agreement on "If I volunteer for medical research, I know my personal information will be kept private and confidential" (z=2.05, p=0.04) and "Medical researchers can be trusted to protect the interests of people who take part in their studies" (z=3.0, p=0.003).

A closer inspection of the relationship between research attitudes and willingness to participate

Table 3 shows the univariate associations between willingness to participate and each of the RAQ items. Although the results are not corrected for multiple comparisons, inspection of the odds ratios suggests that the item assessing the degree that a respondent agrees with "Participating in medical research is generally safe" best predicts willingness to participate (OR = 4.66, $p < 0.001$).

Discussion

We found that compared to adult child caregivers, spousal caregivers had higher willingness to participate in a 21-month long AD dementia clinical trial. They also had a more positive attitude toward research. This difference, however, is confounded with age and possibly reflects age cohort effects. For example, if trust in science has decreased over time, the difference could be due to a cohort effect.

We also found, using a variety of measures of caregiver burden, that burden was not associated with willingness to participate in an AD dementia clinical trial. There was no association between willingness to participate and six measures of burden, including the Screen for Caregiver Burden, caregiver health, or NPI-Q total severity or total distress scores. Instead, the strongest predictor of willingness to participate was research attitudes, with an odds ratio of 1.37 for each average point increase in the 28 point scale.

The limitations of this study include that the research was conducted at a single Alzheimer's Disease Center with a sample of caregivers who were primarily non-Latino whites, thus limiting our ability to draw inferences on the role of race and ethnicity on willingness to participate. In addition, this sample's participation in an annual research registry assessment of disease severity suggests they are already favorably disposed to research. However, investigators typically recruit from such registries for clinical trials and the annual assessment is a minimal risk study. The cross sectional nature of the data limits the ability to infer causation between measures with statistically significant results. Although univariate analyses of burden and willingness to participate were not significant in our sample and we did examine multivariate models that include burden, it is possible that we lacked sufficient power to show relationships within relevant subgroups, such as patients with moderate stage dementia. Finally, the clinical trial the caregivers reviewed was a hypothetical trial and thus the stated willingness to enroll cannot be assumed to exactly equate with actual enrollment.

The finding that caregiver burden is not associated with willingness to enroll in an AD clinical trial is of substantial clinical and ethical value. It suggests that caregivers do not see research as a means to reduce their burden and that there is no prima facie reason therefore to screen out or otherwise limit enrollment based on burden scores. The finding that spousal status is independently associated with willingness to enroll is of notable interest. Although we did not show that it is affected by measures of burden, it may reflect the greater time spouses have to participate as a study partner. Further research is needed to determine whether in fact spouses are more able than nonspouses to perform the many activities related

to being a study partner. Alternatively, it may reflect a spouse's intimate relationship with the patient or an age-cohort effect.

The strong relationship between RAQ scores and willingness to enroll -- even after adjusting for measures of burden, relationship, and dementia severity -- supports that research attitudes may be a powerful and independent predictor of willingness to participate in AD research.[10] This relationship suggests that to the extent that research attitudes are malleable, especially attitudes about the safety of research, then willingness to participate may be malleable as well. Further research is needed to better understand whether interventions targeted to research attitudes can improve willingness to participate. The item-by-item comparison of spousal versus adult child RAQ scores suggests that attitudes related to trust in the research system and in researchers themselves may be particularly salient attitudes. If this is in fact true, then it would add to the data that study partners' willingness to allow their relative to participate is sensitive to the degree of research risk, the probability of assignment to active treatment, and the availability of transportation to the research site.[14]

Study partners are essential participants in AD clinical trials. Although most caregivers are not spouses,[7, 8] study partners are typically spousal caregivers.[9] The more we understand what drives willingness to participate in AD clinical trials, the better researchers can facilitate research recruitment.

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Table 1

Study Partner and Patient Characteristics (n=103).

Measure (possible range)	No. (%) or mean ± SD (range)
Caregiver and patient demographic characteristics	
Spousal caregiver (vs child)	56 (54%)
Caregiver male	32 (31%)
Caregiver race	
white	**80 (78%)**
black	**21 (20%)**
other	**2 (2%)**
Caregiver ethnicity Latino	**3 (3%)**
Caregiver age	62.8 ± 14.8 (32–87)
Caregiver years education	15.7 ± 2.8 (11–24)
Patient male	37 (36%)
Patient race	
white	**79 (77%)**
black	**21 (20%)**
other	**3 (3%)**
Patient ethnicity Latino	**3 (3%)**
Patient age	78.0 ± 8.2 (45–93)
Patient years education	14.2 ± 3.4 (0–20)
Study partner burden	
Financial burden: Just enough or not enough to make ends meet	26 (25%)
Caregiver estimated time to travel to the Penn Memory Center, min.	52.4 ± 35.0 (10–180)
Caregiver health (1–5)	3.8 ± 1.0 (2–5)
Screen for Caregiver Burden* (7–35)	12.1 ± 4.3 (7–25)
Caregiver Geriatric Depression Scale* (0–15)	2.4 ± 2.6 (0–12)
Neuropsychiatric Inventory – Quick form (NPI-Q) total distress score* (0–60)	9.5 ± 8.1 (0–42)
Study partner research attitudes	
Research Attitudes Questionnaire* (7–35)	27.9 ± 3.2 (20–35)
Patient health and dementia severity	
Patient QOL* (1–5)	2.9 ± 1.0 (1–5)
Instrumental Activities of Daily Living* (IADL, 8–31)	20.9 ± 6.0 (8–31)
Basic Activities of Daily Living* (BADL, 6–36)	9.5 ± 4.4 (6–26)
Neuropsychiatric Inventory – Quick form (NPI-Q) total severity score* (0–36)	8.8 ± 6.3 (0–27)

*Higher scores on the measure indicate increasing level, severity or amount of the content the scale measures.

Table 2

Univariate Associations Between Study Partner and Patient Characteristics and Willingness to Participate in AD Clinical Trial.

Measure	Unadjusted OR (95% CI)	p Value
Caregiver and patient demographic characteristics		
Spousal caregiver (vs child)	2.53 (1.26–5.11)	0.01
Male caregiver	2.01 (0.93–4.36)	0.08
Caregiver race white	1.24 (0.55–2.81)	0.61
Caregiver ethnicity Latino	1.13 (0.14–9.24)	0.91
Caregiver age (in decades)	1.39 (1.08–1.77)	0.01
Caregiver years education	1.07 (0.95–1.21)	0.29
Patient male	1.30 (0.64–2.64)	0.47
Patient race white	1.36 (0.60–3.04)	0.46
Patient ethnicity Latino	1.13 (0.14–9.24)	0.91
Patient age (in decades)	1.12 (0.76–1.64)	0.56
Patient years education	1.08 (0.98–1.18)	0.12
Study partner burden		
Financial burden: 1) some money left over, 2) just enough to make ends meet, 3) not enough to make ends meet	1.34 (0.75–2.42)	0.33
Caregiver estimated time to travel to the Penn Memory Center, min.	1.00 (0.99–1.01)	0.63
Caregiver health	1.32 (0.93–1.87)	0.12
Screen for Caregiver Burden	0.99 (0.91–1.07)	0.81
Caregiver Geriatric Depression Scale (15 item)	0.99 (0.86–1.14)	0.89
Neuropsychiatric Inventory – Quick form (NPI-Q) total distress score	0.99 (0.96–1.04)	0.91
Study partner research attitudes		
Research Attitudes Questionnaire	1.39 (1.22–1.57)	<0.001
Patient health and dementia severity		
Patient QOL	1.01 (0.71–1.44)	0.94
Instrumental Activities of Daily Living (IADL)	0.95 (0.90–1.01)	0.10
Basic Activities of Daily Living (BADL)	0.96 (0.88–1.03)	0.21
Neuropsychiatric Inventory – Quick form (NPI-Q) total severity score	0.98 (0.93–1.03)	0.39

Table 3

Associations Between Individual Research Attitudes Questionnaire (RAQ) Items and Willingness to Participate, Univariate Results.

RAQ Item*	OR (95% CI)	p Value
Participating in medical research is generally safe	4.66 (2.54–8.56)	<0.001
Society needs to devote more resources to medical research	2.11 (1.28–3.50)	0.003
If I volunteer for medical research, I know my personal information will be kept private and confidential	2.09 (1.19–3.69)	0.011
Medical research will find cures for many major diseases during my lifetime	1.94 (1.29–2.92)	0.002
We all have some responsibility to help others by volunteering for medical research	1.88 (1.22–2.88)	0.004
I have a positive view about medical research in general	1.86 (1.22–2.81)	0.003
Medical researchers can be trusted to protect the interests of people who take part in their studies	1.12 (0.72–1.75)	0.603

*Each item has values from 1 to 5 with high score indicating more endorsement of the item.