

## Why They Stay: Understanding Research Participant Retention in Studies of Aging, Cognitive Impairment and Dementia

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### Abstract

**Background:** Retaining participants in longitudinal research in aging and Alzheimer's disease remains a significant challenge. "Study partners" are often required to insure participation and accuracy of information because cognitive impairment may interfere with accurate reporting. The purpose of the present report was to identify attitudes and reasons for continued participation in observational research.

**Methods:** 53 individuals (33 participants and 20 study partners) who were participating in the longitudinal cohort at the Mount Sinai Alzheimer's Disease Research Center were available for this survey. They were asked a single open-ended question about why they continued in our study. Seven categories of answers (e.g., Altruism, Value relationship with staff, and Concern about health) were identified and frequency of endorsement was summarized for participants and study partners separately.

**Results:** There were 82 responses from the 53 individuals. Forty five percent of the participants and 55% of the study partners identified altruism as one reason they participate in research over time, and 75% of study partners and 30% of participants mentioned valuing the relationship with staff as a reason they stayed in research.

**Conclusions:** This data suggests that retention efforts should be directed toward fostering strong relationships between research staff and study participants and reinforcing the opportunity to contribute to others, which fosters a sense of altruism.

**Keywords:** Participant Retention, Dementia, Cognitive Impairment

### Introduction

Retention of participants in longitudinal research studies is challenging. Retention in the elderly and among those with cognitive impairment and dementia presents a unique set of difficulties. In the presence of cognitive impairment, an informant or study partner is often required to confirm aspects of history, cognition and performance and to assure compliance with aspects of the research such as attendance, because these participants often are not able to make and keep appointments. Study partners may be family members, paid caregivers or close friends, and their commitment and engagement is crucial in this population.

Investigators need to work with both participants and study partners, which may require keeping track of several individuals for any one research participant. In addition, other issues that are more common in the elderly may also affect research participation, including illness, death, institutionalization, difficulty with ambulation, difficulty arranging transportation to visits, and managing changes in weather, etc. [1]. This is consistent with our center's clinical experience where, in 2011, 93% of families who informed us that they wanted to discontinue participation reported personal illness, life complications (e.g. spouse illness or other stress), or had died during the interval between visits. Retention is a significant issue in

Alzheimer's Disease (AD) research, as trials are moving toward earlier intervention in non-demented or prodromal individuals, and thus successful long-term follow up will be crucial [2].

While we were able to confirm barriers to participation that were consistent with the work of others, we had not considered the motivation for continuing participation. To address this, we chose to conduct a single question qualitative survey asking why participants and their study partners continued to remain engaged in longitudinal research in our Alzheimer's Disease Research Center (ADRC).

### Materials and Methods

Fifty-three individuals from the ADRC at the Icahn School of Medicine at Mount Sinai participated. For our ADRC participants, consent procedures include consent to being contacted concerning research or other programs, as well as the identification of a study partner. This was completed at the onset of their participation in our longitudinal research. All participants were enrolled in this longitudinal cohort, which entails yearly medical and cognitive evaluations. Participants in the longitudinal study are not compensated, though they may be enrolled in related clinical or observational studies that do provide some compensation, and thus may associate compensation with participation in our center. ADRC participants in our center as a whole range from 51 to 102 years old (mean of 78.7 +/- 9.8), are 53% female, and have participated in our

study from 0-8 years (mean of 2.7+/- 2.6). Study partners across our whole center are 21-98 years old (Mean of 64 +/- 15.8) and are 69% female.

Participation in the survey was not associated with clinical or demographic data and no separate consent was obtained. All individuals were asked one question, "We are interested in identifying reasons why research volunteers like you choose to continue participation over time.... can you tell us your main reason(s) for staying?" Individuals spontaneously gave one or more answers to this question and were not probed for further explanations or responses. Forty-seven consecutive participants and study partners were interviewed from September to October 2012 at their yearly visits. Only individuals who were in the center for one or more years were included. In some cases participants and study partners were both interviewed, some participants were too impaired to give responses and therefore just their partners responded, and some participants were cognitively intact and came in without their partners. Data from an additional six study partners were consecutively collected in January 2013 to increase the size of the study partner group. Overall, thirty-three respondents were participants, and 20 were study partners.

Open-ended responses were categorized by 2 senior staff at the ADRC (MS and JN) and the pattern of responses from participants and study partners was tallied by sorting responses into themes and then collaboratively creating categories that best fit those themes. For example, the responses "To see if there can be any benefit to others [from my participation]" and "The ability to help someone else is appealing" were grouped under the category "Altruism."

Data analysis: We used descriptive statistics to summarize responses in each category for participants and study partners separately. Fifteen subjects were randomly chosen for double-scoring and the rate of agreement on observations was 93% with a 95% confidence interval of (65%, 99%).

## Results

Seven categories were identified for the 82 responses (Table 1) (Figure 1).

The most frequent type of response for participants was "Altruism" (45%), followed by "Concern about my health" (42%) (e.g. "I wanted to track my health and see what I could learn") while the most frequent response for study partners was "Value relationship with experts and staff over time" (75%) (e.g. "The staff is friendly and competent" and "So my wife can be seen by world class doctors") followed by "Altruism" (55%). Within the category of "Altruism" both participants and study partners spoke of the hope of finding a cure and pride in helping society (e.g. from a study partner, "We hope our continued participation will add to the data that researchers can use to help find a cure" and from a participant, "it's a win-win, free care, great docs, helps me, helps society.") Interestingly, only approximately 10% of participants and study partners reported feeling obligated to continue in the study.

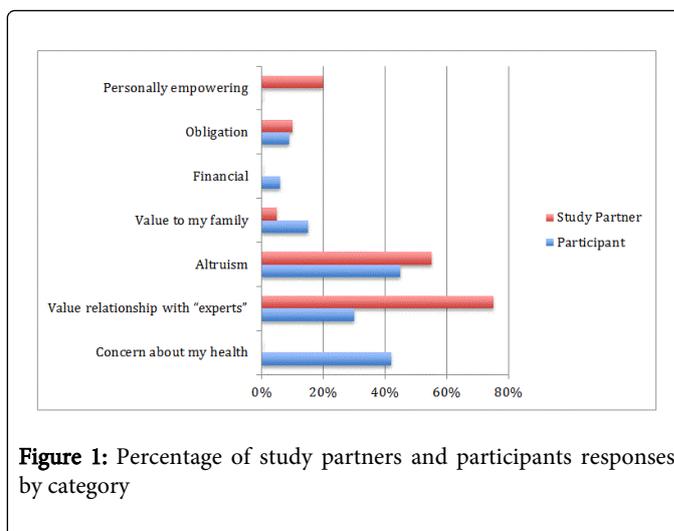


Figure 1: Percentage of study partners and participants responses by category

## Discussion

In our study 75% of study partners and 30% of participants reported that they highly valued the relationship with staff. It may be that study partners are feeling that the relationship with researchers allows for better access to expert care or even advice for the participant. Study partners of cognitively impaired patients are often family members as well as caregivers, and these combined roles may be part of why they value the ongoing contact with experts. In cognitively impaired subjects, retention may be driven by the study partner's view of the value of participation. Clearly this underscores the importance of creating rapport with both participants and their partners to encourage retention.

Nearly half the sample identified altruism as one reason they participate in research over time, giving reasons such as wanting to help find a cure and giving something back to society; this is consistent with other studies [3-5]. A five year study of cardiovascular risk in 2,520 individuals evaluated both reasons for entering and remaining in the trial. Over half of subjects enrolled cited "self-interest" e.g. "health checks" but almost 40% cited altruism. Participants remained in the study because of self-interest, but also because of curiosity concerning study outcome and interactions with the study team [6], which is consistent with our findings.

Financial reward was rarely endorsed by either participants or study partners, although compensation is offered in a few of our associated trials. Furthermore, a sense of obligation was not emphasized. These are important findings to inform Institutional Review Board (IRB) committees as they may mitigate concerns about coercion, which are often part of human subject review. Our data suggests that retention efforts should be directed toward fostering strong relationships between research staff and study partners and participants, and reinforcing the opportunity to demonstrate altruism.

Limitations of this study include the small sample size and the fact that it was a sample of convenience, but these responses identify critical themes, common among participants and study partners which can be evaluated in a larger cohort. A standardized method to assess motivation to participate in research could provide valuable information for both interventional and observational studies. Efforts could then focus on re-enforcing themes associated with participant retention, and to aim to improve retention in upcoming dementia

research. Further studies could also explore differences in retention among individuals with and without cognitive symptoms, and their study partners.

| Type of response                                      | Sample responses:   |
|---|---|
| Personally empowering                                 | "Helps me take control of this."  |
| Obligation  | "My wife makes me." "I made a commitment to [my doctor]."   |
| Financial   | "It's free care." "Being paid is a perk."   |
| Value to my family                                    | "(AD) runs in my family, so maybe this means my children will be free of it."   |
| Altruism  | "I want to help defeat the terrible problem of AD." "If I can help, why not?" "Gives me pride to help." "Research is how we get answers." |
| Value relationship with "experts" and staff over time | "Couldn't do this without [the doctor]." "Staff are so uplifting. Look forward to it." "They make me feel less alone."                    |
| Concern about my health                               | "I'm 93, I need to have memory checked frequently." "I want to see if I decline over time."   |

**Table 1:** Percentage of study partners and participants responses by category.

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