

RESEARCH ARTICLE

Barriers to seeking care for memory problems: A vignette study

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Abstract

Introduction: This study compares how older adults judge the need for follow-up care for memory-related problems when they are responding about themselves versus someone of the same age.

Methods: Adults ages 65 and over in the Understanding America Study, a nationally representative internet panel, were invited to participate in a short survey with three vignettes describing memory-related problems associated with normal aging, mild cognitive impairment, and mild dementia. Respondents were randomly assigned to vignettes about themselves or about an individual of the same age and asked whether the problems warranted follow-up discussion with a health-care provider. Unadjusted and covariate-adjusted differences in the percent of affirmative responses to follow-up discussion and an index, ranging from 0 to 3, that summed affirmative responses, were compared across respondents randomly assigned to self- versus other-framed vignettes.

Results: One thousand six hundred twenty-eight panel members (81.6%) completed the survey (mean age, 72.3 [range, 65–102], 801 female [49.2%] and 827 male [50.8%]) with 796 (48.9%) randomly assigned to vignettes about themselves and 832 (51.1%) to vignettes about individuals of the same age. Percent affirming need for follow-up ranged from 66.9% to 90.5% and was systematically lower for those randomized to vignettes about themselves. The differences ranged from –10.8 percentage points (95% confidence interval [CI], –13.6 to –7.9 percentage points) for the most severe to –13.9 percentage points (95% CI, –18.1 to –9.7 percentage points) for the mildest memory-related problem vignettes. The summary index was –0.444 points (95% CI, 0.563 to –0.326) or 0.491 of a standard deviation (95% CI, 0.622 σ to –0.362 σ) lower for scenarios about participants themselves relative to others.

Discussion: Seniors were more likely to recognize and recommend follow-up for memory-related problems affecting someone else than the same problems affecting themselves, suggesting symptom education alone may not improve rates of cognitive assessment for detection of impairment and dementia.

KEYWORDS

follow-up care, memory-related problems, vignette study

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1 | INTRODUCTION

Between 15% and 40% of dementia cases and an even higher share of mild cognitive impairment (MCI) cases are undiagnosed.^{1,2,3} As a result, clinical diagnosis of dementia often occurs late in the disease trajectory,^{4,5} hindering timely treatment of reversible causes of memory loss, treatment to manage symptoms, acquisition of knowledge about the disease, and enrollment in clinical trials, and complicating the patient's and family's ability to develop medical, legal, and financial plans.^{6,7} Recently, the US Food and Drug Administration granted approval to aducanumab (brand name Aduhelm), the first treatment on the market aimed at slowing the progression of Alzheimer's disease (AD). Aducanumab trials and other clinical development of drugs with disease-modifying effects typically target persons at preclinical or prodromal stages of disease. Furthermore, study on other non-pharmacological approaches to preventing or slowing cognitive decline at early-stage disease has expanded. Improving early detection of cognitive decline to reduce or delay onset of AD is necessary to reduce the global burden of AD.

Dementia and MCI are overwhelmingly diagnosed in primary care.⁸ The Affordable Care Act (ACA) promotes early detection of dementia through the Medicare annual wellness visit (AWV), a comprehensive primary care visit that requires, among other things, that providers detect cognitive impairment. The rate of annual wellness visits however, is low, about 30% in 2018, and only about half of those had a structured assessment at the visit.⁹ The implication, supported by data, is that detection of cognitive impairment in the primary care setting is often based on clinician observation and patient self-reports.¹⁰

The reasons that systematic approaches to detection are not more commonly used in primary care are multifaceted and include both provider- and patient-specific factors. An expert panel of clinicians and cognitive neuroscientists identified multiple challenges to widescale cognitive assessment related to physician training, support tools, and medical practice.¹¹ Unwillingness to undergo cognitive assessment,^{12,13} which is sensitive to perceived risk and severity of dementia and perceived benefits of screening, is also a common barrier.^{14,15,16,17,18,19} Lack of knowledge, low awareness of dementia, normalization of symptoms, and stigma and denial are also commonly identified patient and caregiver barriers to screening.^{20,21,22,23} Communication constraints among providers, patients, and caregivers likely compound these issues.⁶

In this work, we sought to assess whether factors including, but not limited to, denial and/or overoptimism play a role in the reluctance of individuals to seek care for memory problems, holding constant beliefs about the potential value of such care. To do this, we used a vignette study that randomized participants to standardized memory problem scenarios affecting the respondent herself or affecting an individual of the same age. The key prediction was that individuals would be more likely to recommend follow-up discussion for memory-related problems affecting someone else than the very same problems affecting oneself. Such a differential is consistent with either a more optimistic interpretation of the data, that is, cognitive dissonance, or a reluctance to act on data when it pertains to oneself.

HIGHLIGHTS

- Most older adults recommend health-care provider follow-up for memory problems.
- Recommendation rates are lower for their own than another's memory problems.
- Provider reliance on patients' report of their memory problems may limit detection.
- Approaches to overcome bias against care for one's memory problems are needed.

RESEARCH IN CONTEXT

1. **Systematic review:** Patient-specific barriers to cognitive screening identified in the published literature tend to focus on patient awareness of symptoms and the psychological burden of screening.
2. **Interpretation:** In this vignette study, older adults randomized to memory problem scenarios affecting themselves were about 10 to 13 percentage points less likely to recommend follow-up than those randomized to the same problem scenarios affecting someone else of the same age. Symptom education and provider assessment of memory problems based on patient reports are likely insufficient to improve detection of cognitive impairment because individuals may be overly optimistic about their own symptoms or for other reasons be less eager to seek follow-up for those symptoms relative to what they recommend for others.
3. **Future directions:** Future work should assess the relationship between screening intentions and actions and test interventions to overcome individual bias against seeking care for one's memory problems.

2 | METHODS

We designed and fielded a survey to people 65 and older who are part of the Understanding America Study (UAS). This nationally representative panel of ~8000 people ages 18 and older residing in the United States is maintained by the Center for Economic and Social Research at the University of Southern California. UAS surveys are conducted online, using a computer, tablet, or smartphone.²⁴ People without online access are provided with a tablet and an internet subscription. The UAS has been used previously to study receipt of structured cognitive assessments about seniors enrolled in Medicare.⁹ Respondents received \$6 in compensation for survey completion based on a median response time of 6 minutes. The full text of the survey and the data are available on the UAS website under "UAS 284." The University

of Southern California's Institutional Review Board approved the data collection as an amendment to UP-14-00148.

All 1994 English-speaking adults ages 65 and over in the panel were invited to the study between April 14, 2021, and May 19, 2021. One thousand six hundred twenty-eight participants or nearly 82% completed the survey. Survey respondents answered questions about their health insurance and then reviewed three memory-problem vignettes that varied by severity of memory issues. Respondents were randomized in advance based on single year of age or age 85 and over to vignettes affecting themselves or to the same vignettes affecting a person of the same age. Within each set (self or other person of the same age), the order of appearance of the three vignettes was further randomized. After each vignette, respondents were asked whether the problem warranted discussion with a health-care provider at the next appointment or the scheduling of an appointment to discuss the problem. After completing the vignettes, respondents were asked additional questions about their receipt of cognitive screening in the past 12 months and about their health and health care more generally. The final dataset included demographic and socio-economic information collected previously by the panel.

2.1 | Vignettes

The three vignettes varied by severity of memory issues with vignette 1 representing the least severe and vignette 3 representing the most severe memory issues

Vignette 1, which reflected normal aging-related memory loss, described the respondent or Jane Smith with an excellent memory who recently had difficulty coming up with the names of casual acquaintances, trouble finding words, and sometimes forgot why she walked into another room. The vignette also described difficulty sleeping due to financial concerns.

Vignette 2, which conveyed MCI, described the respondent or Bob Smith with excellent long-term memory but short-term memory problems and frequent repeating of questions within a span of a few minutes. Out of character, he has accidentally missed two doctor's appointments and a friend's birthday dinner this past year and missed his exit on the freeway recently and needed to get directions on how to get home.

Vignette 3, which captured mild dementia, described the respondent or Paula Smith as experiencing a worsening of memory problems that have been mild for the past couple years. She takes longer balancing her checkbook, has overdrawn her account after sending in a mortgage payment twice, often forgets to take her blood pressure medicine, and has difficulty retaining information and using an iPad to video-chat with her grandchildren.

2.2 | Outcome measures

Measures were percent of affirmative responses for follow-up discussion with health-care providers for each of the three vignettes, and

an index summing affirmative responses across vignettes with a range from 0 to 3.

2.3 | Statistical analysis

For each vignette, we tested the difference in the rate of recommending follow-up discussion when the vignette was about the respondent relative to a hypothetical other person of the same age. We also tested the difference in the mean index for respondent-focused relative to other person-focused vignettes. To increase precision, we estimated linear regression models that tested for differences adjusted for random assignment strata. To adjust for any confounding factors not addressed by the age-stratified randomization, we also estimated linear regression models that adjusted for race (White, Black, American Indian, Asian/Pacific Islander, more than one race), Hispanic/Latino ethnicity, sex, education (less than high school degree, high school or GED, some college, associate degree, bachelor's degree, master's degree or higher), household income (below \$15,000, \$15,000–24,999, \$25,000, \$35,000, \$50,000, \$75,000, and \$150,000+), retirement status, and Medicare coverage. Because the randomization did not use survey weights, the primary analysis was unweighted. Sensitivity checks using survey weights were performed.

3 | RESULTS

Of the 1628 panel members ages 65 and over (81.6%) who responded to the survey, 796 (48.9%) respondents were randomly assigned to vignettes about themselves and 832 (51.1%) to vignettes about individuals of the same age (Table 1). The mean age of respondents was 72.3 (range, 65–102), with 71% between the ages of 65 and 74. One thousand four hundred twenty-two (87.6%) were White and 827 were male (50.8%). More than half had an associate degree or higher and most had income of \$50,000 or more. Among respondents, 1280 (78.6%) were retired and 1419 (88.3) reported having Medicare coverage. None of these characteristics differed between the groups randomized to vignettes about someone of their own age ("Other") versus vignettes about themselves ("Self").

Rates of recommendation for follow-up discussion were high for all vignettes (Table 2). Among those randomly assigned to vignettes about someone else of the same age, 73.4% recommended follow-up for vignette 1, 95.6% for vignette 2, and 95.1% for vignette 3. As illustrated in Figure 1, the rate of recommendation for follow-up discussion was systematically lower if the vignettes pertained to the respondent ("Self") relative to someone else of the same age ("Other"). Unadjusted rates of follow-up recommendation were 13.9 percentage points lower for vignette 1 and 11 and 10.8 percentage points lower for vignettes 2 and 3, respectively, when they pertained to the respondent relative to someone else of the same age.

The same pattern was found in the summary index (Figure 2). The index was 0.356 index points or about half a standard deviation lower when it referenced respondents compared to other persons of the

TABLE 1 Summary statistics and randomization check

| | Overall | Other | Self | P-value |
|-------------------|-------------|------------|------------|---------|
| Age | | | | |
| Mean (SD) | 72.3 (5.9) | 72.3 (5.9) | 72.3 (6.0) | .937 |
| Age group | | | | |
| 65–74 | 1150 (70.6) | 586 (70.4) | 564 (70.9) | |
| 75–84 | 407 (25.0) | 214 (25.7) | 193 (24.2) | |
| 85+ | 71 (4.4) | 32 (3.8) | 39 (4.9) | .497 |
| Race | | | | |
| White | 1422 (87.6) | 725 (87.2) | 697 (88.0) | |
| Black | 83 (5.1) | 47 (5.7) | 36 (4.5) | |
| American Indian | 14 (0.86) | 7 (0.8) | 7 (0.9) | |
| Asian/PI | 51 (3.1) | 27 (3.2) | 24 (3.0) | |
| More than one | 53 (3.3) | 25 (3.0) | 28 (3.5) | .841 |
| Hispanic/Latino | 75 (4.6) | 36 (4.3) | 39 (4.9) | .582 |
| Education | | | | |
| Less than HS | 64 (3.9) | 39 (4.7) | 25 (3.1) | |
| HS or GED | 267 (16.4) | 137 (16.5) | 130 (16.3) | |
| Some college | 378 (23.2) | 210 (25.2) | 168 (21.1) | |
| AA degree | 204 (12.5) | 106 (12.7) | 98 (12.3) | |
| Bachelor's degree | 371 (22.8) | 182 (21.9) | 189 (23.7) | |
| Master's degree | 344 (21.10) | 158 (19.0) | 186 (23.4) | .080 |
| Male | 827 (50.8) | 413 (49.6) | 414 (52.0) | .339 |
| Household Income | | | | |
| 14,999 or below | 137 (8.5) | 64 (7.7) | 73 (9.2) | |
| 15,000 to 24,999 | 164 (10.1) | 98 (11.9) | 66 (8.3) | |
| 25,000 to 34,999 | 166 (10.2) | 89 (10.8) | 77 (9.7) | |
| 35,000 to 49,999 | 238 (14.7) | 127 (15.4) | 111 (14.0) | |
| 50,000 to 74,999 | 364 (22.5) | 184 (22.3) | 180 (22.6) | |
| 75,000 to 149,999 | 420 (25.9) | 202 (24.5) | 218 (27.4) | |
| 150,000 or more | 132 (8.1) | 62 (7.5) | 70 (8.8) | .156 |
| Retired | 1280 (78.6) | 660 (79.3) | 620 (77.9) | .479 |
| Medicare covered | 1419 (88.3) | 725 (88.6) | 694 (87.8) | .626 |
| Observations | 1628 | 832 | 796 | |

Notes: Data are for seniors in the Understanding America Study, survey 284. P-value is for the difference between columns 2 (“other”) and 3 (self). Abbreviations: AA, associate degree; GED, General Educational Development; HS, high school; PI, Pacific Islander; SD, standard deviation.

same age. Tests for heterogeneity in the self relative to other difference in the index were generally imprecise, with the exception of a larger difference between self and other for respondents with no college compared to college educated respondents (Figure 2 and Table S3 in supporting information).

Adjusting for randomization (age by question order) strata (Table 2 col 2) or strata and sociodemographic covariates (Table 2 col 3) had little impact on these differences. Results were robust to use of survey weights as well (see Figure S1 and Tables S1 and S2 in supporting information).

4 | DISCUSSION

Across all three vignettes, rates of recommendation for follow-up discussion about memory problems with providers were very high (>70%). These high rates are somewhat surprising given that older adults, including those reporting subjective memory complaints, infrequently discuss either dementia risk or memory problems with providers.^{25,26} However, this gap is consistent with the “intention-behavior gap” common to many health behaviors.²⁷

TABLE 2 Difference in follow-up by assignment

| | Raw difference | Strata controls | Full controls |
|------------------------------------|-----------------------------|-----------------------------|-----------------------------|
| Panel A: Vignette 1 | | | |
| Self | -0.139 (-0.181 – -0.097) | -0.135 (-0.180 – -0.090) | -0.131 (-0.176 – -0.085) |
| Follow-up | 0.734 | 0.734 | 0.734 |
| Observations | 1628 | 1628 | 1616 |
| R-squared | 0.022 | 0.133 | 0.147 |
| Panel B: Vignette 2 | | | |
| Self | -0.11 (-0.138 – -0.081) | -0.11 (-0.140 – -0.080) | -0.111 (-0.141 – -0.081) |
| Follow-up | 0.956 | 0.956 | 0.956 |
| Observations | 1628 | 1628 | 1616 |
| R-squared | 0.035 | 0.162 | 0.193 |
| Panel C: Vignette 3 | | | |
| self | -0.108 (-0.136 – -0.079) | -0.107 (-0.137 – -0.076) | -0.103 (-0.133 – -0.074) |
| follow-up | 0.951 | 0.951 | 0.951 |
| Observations | 1628 | 1628 | 1616 |
| R-squared | 0.033 | 0.169 | 0.227 |
| Panel D: Vignette Assessment Index | | | |
| Self | -0.356 (-0.438 – -0.274) | -0.351 (-0.438 – -0.264) | -0.345 (-0.433 – -0.257) |
| Mean index (s.d. index) | 2.64 (0.646) | 2.64 (0.646) | 2.64 (0.646) |
| Observations | 1628 | 1628 | 1616 |
| R-squared | 0.045 | 0.163 | 0.186 |

Notes: Rows labeled “self” show the estimated difference in follow-up recommendations for a vignette about oneself relative to a vignette about someone else of the same age. 95% confidence intervals are shown in parentheses. Follow-up rates and the mean index are for the sample assigned to vignette about other people.

More telling than the rate of recommendation, memory-related problems that were recognized in others as warranting follow-up discussion with a health-care provider were more likely to be dismissed as not requiring follow-up when they were one’s own symptoms. In other words, individuals were either more optimistic about symptoms affecting themselves or otherwise more reluctant to seek care for these symptoms. The results were robust across descriptions of clinically significant memory-related issues. Notably, the effect size was largest (13 percentage points) for symptoms associated with normal aging, which generally do not require clinical evaluation. The findings are generalizable to persons ages 65 and older in the United States. The randomized study design and sample size allowed for identifying the effect independent of unmeasured factors such as knowledge or awareness about cognitive impairment for precise and rigorous estimates.

The findings are important given how infrequently older adults report discussing dementia risk with providers, the low rates of cognitive assessment among older Americans, and the significant percentage of older adults with cognitive impairment and dementia who do not receive a diagnosis. Only \approx 5% of older adults did not agree that

the clinically significant symptoms (vignettes 2 and 3) of others warranted follow-up care or discussion with a health-care provider, but this increased to about 15% when symptoms were described as one’s own. This suggests that barriers to seeking care go well beyond a lack of awareness of symptoms. Overoptimism as well as denial about dementia or fear of uncovering cognitive decline also play a role. These factors may be particularly acute due to not only stigma, but also limited treatments for dementia; concern for loss of independence; and among workers, apprehension about employment loss. Reducing barriers to assessment could increase the numbers of patients who receive assessment and early diagnosis but barriers to care seeking, such as the one identified through this study, must be addressed.

Most patients with memory-related issues will be diagnosed in primary care, where structured assessment tools are not often used, and providers often rely on self-reports of memory concerns.^{8,9} The AWW specifically requires “detection of any cognitive impairment,” defined as “assessment of an individual’s cognitive function by direct observation, with due consideration of information obtained by way of patient report, concerns raised by family members, friends, caretakers or oth-

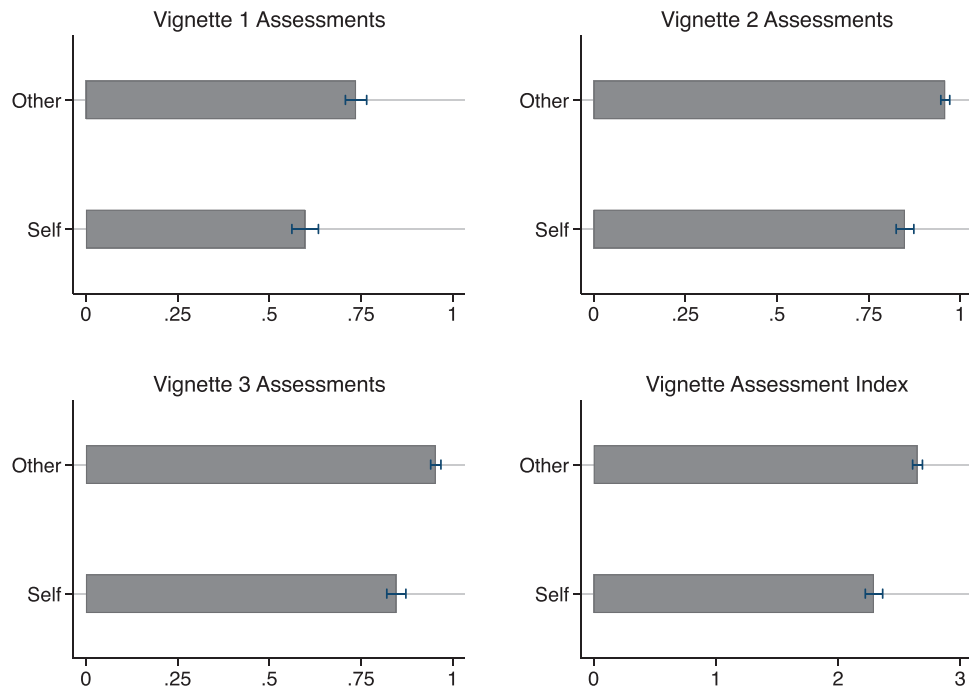


FIGURE 1 Recommendation for follow-up by vignette and assignment type. Notes: Bars show the rate of recommendation for follow-up or the mean assessment index by vignette and random assignment type (self or other). The vignette assessment index is just the sum of each respondent's recommendation for follow-up across all three scenarios

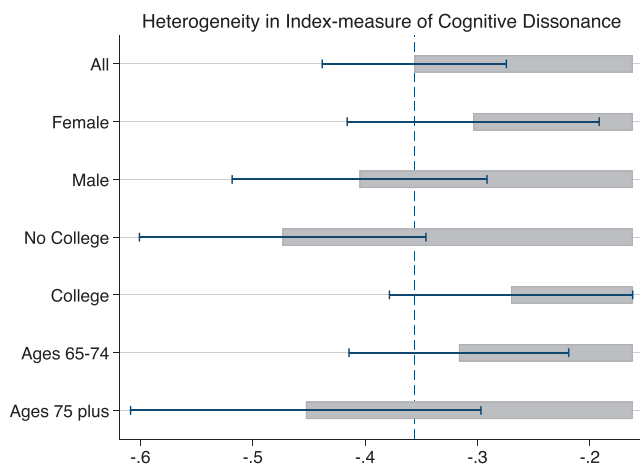


FIGURE 2 Difference in the Vignette Assessment Index: self relative to other. Notes: Bars show the mean index difference for oneself relative to others by group. The capped lines represent the 95% confidence intervals. The dashed vertical line shows the mean difference for the full sample

ers.” These results suggest that health-care providers’ assessments obtained by way of patient report, an approach commonly used at the AWV and other health-care visits,¹⁰ will result in lower detection of impairment than if providers systematically deploy brief cognitive assessments.

To access the potential individual and societal-level benefits to early diagnosis, physician, health-care system, and patient-level barriers

need to be addressed. This includes but is not limited to barriers to screening. Some patients who do seek care and receive a positive screen for dementia refuse a diagnostic assessment.²² Research on the value of screening for cognitive assessment is an additional gap identified by the US Preventive Task Force.

Limitations to the study include limited sample size for precision in analysis of heterogeneity across multiple demographic and socioeconomic factors. Future work should investigate heterogeneity for insight into targeted opportunities to increase assessment rates.

5 | CONCLUSIONS

This study finds that when memory-related problems are described as affecting someone else of the same age, most persons recommend a follow-up discussion with a health-care provider. When the very same problems are described as one’s own symptoms, individuals are systematically less likely to see the need for follow-up care. These data suggest that more routine cognitive assessment in older adults, rather than relying on patient-reported memory problems, may be needed to improve early detection of cognitive impairment and to improve population brain health.

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CONFLICTS OF INTEREST

MJ discloses a retainer from a law firm representing hospitals across the country in ongoing litigation against opioid manufacturers and distributors. EJ discloses receiving an honorarium for presenting at USC's The Science of ADRD for Social Scientists. JZ discloses serving on the Advisory board, P30 Center, University of Texas, Austin Working Group on dementia for GSA.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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