Published in final edited form as:

J Alzheimers Dis. 2020 ; 74(2): 625–636. doi:10.3233/JAD-190922.

How Accurately Do Patients and Their Care Partners Report Results of Amyloid- β PET Scans for Alzheimer's Disease Assessment?

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Abstract

Background: Amyloid- β PET scans will likely become an integral part of the diagnostic evaluation for Alzheimer's disease if Medicare approves reimbursement for the scans. However, little is known about patients' and their care partners' interpretation of scan results.

Objective: This study seeks to understand how accurately patients with mild cognitive impairment (MCI) or dementia and their care partners report results of amyloid- β PET scans and factors related to correct reporting.

Methods: A mixed-methods approach was used to analyze survey data from 1,845 patient-care partner dyads and responses to open-ended questions about interpretation of scan results from a sub-sample of 200 dyads.

Results: Eighty-three percent of patients and 85% of care partners correctly reported amyloid- β PET scan results. Patients' higher cognitive function was associated with a small but significant decrease in the predicted probability of not only patients accurately reporting scan results (ME: –

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Authors' disclosures available online (<https://www.j-alz.com/manuscript-disclosures/19-0922r2>).

0.004, 95% CI: -0.007, -0.000), but also care partners accurately reporting scan results (ME: -0.006, 95% CI: -0.007, -0.001), as well as decreased concordance between patient and care partner reports (ME: -0.004, 95% CI: -0.007, -0.001). Content analysis of open-ended responses found that participants who reported the scan results incorrectly exhibited more confusion about diagnostic terminology than those who correctly reported the scan results.

Conclusion: Overall, patients with MCI or dementia showed high rates of accurate reporting of amyloid- β PET scan results. However, responses to questions about the meaning of the scan results highlight the need for improved provider communication, including providing written explanations and better prognostic information.

Keywords

Alzheimer's disease; amyloid PET; caregivers; dementia; mild cognitive impairment

INTRODUCTION

Though disease-modifying Alzheimer's disease (AD) treatments are not yet available, the disease's devastating symptoms, prevalence among older adults, and substantial cost burden have put mounting pressure on health care systems to identify persons with AD [1, 2]. Amyloid- β PET scans can improve diagnostic confidence among patients with cognitive decline and sometimes lead to a change in care management [3–7]. According to a study of 229 patients with history of cognitive decline and uncertain diagnosis, after receiving the results of the amyloid- β PET scan (113 amyloid positive, 116 amyloid negative), diagnosis changed in 54.6% of patients, diagnostic confidence increased by an average of 21.6%, and 86.9% of patients had at least one change in their management plan [5]. Additionally, changes in amyloid- β can provide the earliest detectable signs of AD [3]. Amyloid- β PET results and CSF amyloid- β levels (CSF A β_{42}) are highly correlated [8], but amyloid- β PET is believed to be the most suitable surrogate *in vivo* marker for amyloid load due to the high correlation with histopathology.

Recognizing the potential value of amyloid- β PET scans for diagnosis of AD, the Centers for Medicare & Medicaid Services (CMS) has made initial steps toward covering payment of these scans. In 2013, CMS issued a National Coverage Determination that allows conditional coverage of amyloid PET scans for patients with Medicare as their primary payer and who meet specific appropriate use criteria including being enrolled in an approved clinical trial. This trial coverage period included a study, Imaging Dementia—Evidence for Amyloid Scanning (IDEAS), designed to assess if use of amyloid- β PET scans is associated with subsequent changes in the management of patients with mild cognitive impairment (MCI) or dementia of uncertain etiology. Recently published results from the IDEAS study demonstrated that amyloid PET scans substantially impact clinical management and etiologic diagnosis of dementia [9]. The study included 11,409 patients and reported a change in clinical management for 60.2% of patients with MCI and 63.5% of patients with dementia. Additionally, in 25.1% of patients, etiologic diagnosis changed from AD to non-AD, and in 10.5% of patients, the etiologic diagnosis changed from non-AD to AD.

There is limited research on how accurately cognitively impaired patients and their care partners understand amyloid PET scan results. One study of 30 MCI patients and their care partners found that most understood the results and limitations of results, but 20% still equated elevated amyloid as a definitive marker of AD [10]. Amyloid- β PET scans provide information on risk of continued cognitive and functional decline and can aid in future care planning. Patients' and care partners' accurate reporting of the results is a critical first step in being able to plan for future care.

However, there is an important differential in utility of positive scan results depending on level of cognitive impairment. For dementia patients with a clinical phenotype of AD, a positive amyloid- β PET scan result provides support for a diagnosis of AD versus other causes of dementia. For patients with MCI, a positive scan provides more limited information: MCI patients are at increased risk for progression to AD dementia [11]. Underscoring the indeterminate information gained from a positive result for MCI patients, a recent study of 232 patients with amnesic MCI found that 53.6% of patients with positive amyloid- β results progressed to probable AD by 36 months compared to 23% of those with a negative amyloid result [12]. Given these uncertainties, it is important that patients and their care partners understand the limited definitiveness of positive results particularly for MCI patients. Further, care partners of MCI patients have an opportunity to learn patient's values and preferences to inform future decision making if patients' experience further cognitive decline [13], which emphasizes the importance of care partners' understanding of scan results.

The purpose of this study was to 1) understand how accurately patients with MCI or dementia and their care partners report results of amyloid- β PET scans and the concordance between their reports, 2) identify factors that influence correct reporting of scan results and concordance within the patient-care partner dyad, and 3) provide qualitative insights into patients and their care partners' difficulties in accurately reporting results.

MATERIALS AND METHODS

Patient population and study protocol

The study population was drawn from the Imaging Dementia—Evidence for Amyloid Scanning (IDEAS) study, a cohort study examining the impact of amyloid- β PET scans on clinical outcomes among Medicare beneficiaries with MCI or dementia [14]. MCI and dementia were diagnosed based on standard criteria (DSM-IV and/or National Institutes of Aging-Alzheimer's Association criteria [15, 16]) and verified by a dementia specialist within 24 months. To be eligible for inclusion, participants had to be Medicare beneficiaries age 65 or older referred by a qualified dementia specialist and meet Appropriate Use Criteria (AUC) to receive an amyloid- β PET [17]. Detailed inclusion and exclusion criteria for the IDEAS study are provided elsewhere [14, 18].

As a part of the IDEAS study, amyloid- β PET scans were performed and interpreted at each participating PET facility. Results were then provided to the ordering provider. Study protocol specified that providers disclose the PET scan results, preferably in person, to patients and care partners as a part of clinical care with no specified timeframe; however,

best practices suggest disclosure should be done as soon as possible. The date of disclosure of the scan results was not documented in the study records.

The CARE-IDEAS study, a supplemental study to the parent IDEAS study, was proposed during the IDEAS recruitment phase prior to receipt of IDEAS data. The objective of the CARE-IDEAS study was to bring the voice of the patient into the largest study using a biomarker to improve the diagnosis of AD. This concurrent mixed-methods study links amyloid scan data with clinical history and assessment data, complete Medicare utilization information, and patients' and care partners' reports of their experience [19]. CARE-IDEAS patient participants were identified by their indication of willingness to participate in supplemental IDEAS studies and were subsequently contacted by a survey research firm by mail. The mailing explained the CARE IDEAS study, informed the patient that s/he would be contacted by an interviewer from the survey firm, and requested this information be given to his/her care partner. Only those patients who were willing to identify a care partner were included. To participate in CARE-IDEAS, the patient had to have received the results of the amyloid PET scan prior to the telephone interview. At the beginning of the CARE-IDEAS telephone interview, the patient and care partner were asked whether the patient had received the results of the amyloid PET scan. Of the 3,717 IDEAS study patients who initially agreed to be contacted, 2,228 of them and 1,872 of their care partners completed baseline survey questionnaires.

Interviewers from the research firm Westat administered survey questionnaires by phone among patients and care partners separately. Patients were asked to answer by themselves and this was reminded to them if interviewers could hear care partners intervening. Interviews lasted for about 30 minutes for patients and 45 minutes for care partners.

The current study used data from the CARE-IDEAS baseline surveys of both the patient and the care partner, as well as data on the patients' amyloid- β PET scan results and other baseline information obtained from the parent IDEAS study. Our sample was limited to 1,845 dyads where the scan result was definitive positive or negative for amyloid- β and both patient and care partner reported a result. A definitive positive or negative result was required for inclusion both to understand how accurately respondents reported results and understood the results. The Brown University Institutional Review Board approved the CARE-IDEAS study (#1606001534).

Measures

Both members of the patient care partner dyad reported sociodemographic characteristics including age, gender, race, and educational attainment. Patients and care partners provided their responses to a five-point Likert scale to indicate their level of health literacy with one being always needing help reading hospital materials and five being never needing help reading hospital materials [20].

Cognitive status of patients and care partners was assessed using an abbreviated version of the Telephone Interview Cognitive Status (TICS-M). The TICS-M is one of the most frequently used telephone cognitive screening instruments to detect cognitive change and dementia [21, 22]. The scores for the abbreviated version of the TICS-M range from 0–35,

and the instrument includes items of immediate and delayed 10-noun free recall; serial seven subtraction; counting backwards; recall of the date, naming the president and the vice-president; and naming two common items.

Finally, care partners reported their relationship to the patient and answered questions from the communication domain from the CAPACITY instrument. The CAPACITY instrument is a validated measure of Caregiver Perceptions About Communication with Clinical Team members [23]. The instrument measures caregivers' perceptions of care team interactions in two domains: quality of communication with the health care team and health care team's consideration of the care partner's capacity and preferences for caregiving. This study calculated the CAPACITY communication domain score by taking the average of each of the six communication domain questions (range 1–4) where a higher score indicates better perceived communication from the care team.

Primary quantitative outcome measures included patient and care partner accurate report of amyloid- β PET scan results—result concordance—and the concordance between patients and their care partner's reports—dyadic concordance. Result concordance was defined as concordance between the participants' report of the result and the actual result independent of the result (e.g., respondent reported scan positive for amyloid and actual result was positive or respondent reported scan negative for amyloid and actual result was negative). Accuracy of scan report was defined as when the result recorded by participating providers (i.e., positive or negative for amyloid) matched patient and care partners' answer to the question, "What were the results?" In administering this survey question, interviewers provided the response options, "positive result or negative result." Interviewers had been told a positive result is indicative of Alzheimer's disease, so if a patient responded with a contradictory statement (e.g., "the results were positive, no Alzheimer's"), the interviewer was instructed to ask for clarification. Dyadic concordance was defined as concordance between patients and their care partner's report of the scan results independent of accuracy of reporting.

A subset of patients ($N = 1,013$) and care partners ($N = 794$), on their baseline survey, were asked an additional four and five open-ended questions, respectively. In this study, we analyzed a sub-sample of the responses to those questions ($n = 202$ dyads), particularly the first one: "According to the doctor, what do the results of the amyloid PET scan mean?"

Statistical analysis

We described patient characteristics by dementia or MCI diagnosis including: demographic information (e.g., age, Caucasian race or not, gender, education level), cognitive status as measured by the abbreviated TICS-M score, and health literacy. Description of care partner includes all of the above characteristics with the addition of relationship to the patient and CAPACITY Communication score. We used single imputation for missing values for patient age ($n = 9$), care partner age ($n = 11$), and CAPACITY Communication score ($n = 125$) replacing the missing value with the median value for that variable.

To understand how accurately patients with MCI or dementia and their care partners report results of amyloid- β PET scans, we constructed two-by-two matrices for result concordance

—one for the patient and one for the care partner. In both the patient and care partner matrices, we report the rate of accurate report defined as the proportion of patients or care partners whose self-report of the scan result correctly matches the actual scan result. Given that amyloid- β PET scan result provides less determinant information regarding prognosis and diagnosis for MCI compared to dementia patients, and that this may affect accurate reporting, we also provide result concordance matrices broken out for MCI and dementia patients and their care partners. We use Pearson chi-square to examine the relationship between patient cognitive status (MCI versus dementia) and accurate reporting among patients and care partners. To understand dyadic concordance, we constructed a two-by-two matrix to describe the rate of dyadic concordance.

To identify factors that influence correct reporting of scan results and concordance within the patient-care partner dyad, we used univariate and multivariate logistic regression models to analyze the association between patient and care partner characteristics and outcomes of interest: 1) patient result concordance, 2) care partner result concordance, and 3) dyadic concordance. We ran univariate regression on each outcome for each of the following predictor variables: patients' diagnosis of MCI versus dementia, patients' and care partners' cognitive function score, age, race, education, gender, and health literacy, the difference in years between the age of the patient and the caregiver, care partners' relationship to patient, and CAPACITY communication domain score. Then we included all predictor variables in each multivariate outcome model. We report estimated marginal effects. All analyses were conducted using STATA, version 14 (StataCorp, College Station, TX).

Qualitative data collection and analysis

Of the 1,013 patients and 794 care partners who provided responses to open-ended questions, responses from 202 dyads were transcribed verbatim to explore patients' and care partners' interpretations of scan results. Analyses of 100 dyads were completed first followed by 102 more dyads to confirm saturation had been reached, whereby coding new interviews did not provide any original themes or content. Patients and care partners were asked, "According to the doctor, what do the results of the amyloid PET scan mean?" The responses to this open-ended question were linked with the survey responses to the question of "What were the results?" using the NVivo 12 software to focus on participants who inaccurately reported scan results. The open-ended responses were analyzed by two authors (EB, TW) using qualitative content analysis and any divergences were discussed until consensus was reached [24]. The two authors EB and TW agreed that saturation had been reached after analyzing the 202 dyads.

RESULTS

Patient and care partner characteristics

The CARE-IDEAS baseline survey was conducted a median of 4.5 months post scan. In 496 of the 1,845 patient-care partner dyads, the patient had dementia, and 1,349 had MCI (Table 1). Patients were nearly all Caucasian (95.8% dementia, 96.4% MCI), majority male (59.9% dementia, 60.5% MCI) with average age of 75 years, and more than half had a bachelor's or higher degree (53.8% dementia, 61.6% MCI). Care partners were also nearly all Caucasian

(95.9%), majority female (67.8%), majority with a bachelor's or higher degree (58.0%), and typically the patients' spouse or significant other (87.1% for dementia, 88.7% for MCI). Patients with MCI differed from patients with dementia on three characteristics: TICS-M score ($p < 0.0001$), which is expectedly higher for patients with MCI; Education ($p < 0.0001$) with patients with MCI being more educated; and health literacy ($p < 0.0001$) with patients with MCI reporting needing less help reading hospital materials.

Result and dyadic concordance

Nearly 83% of patients and 85% of care partners correctly reported the results of the amyloid- β PET scan (Table 2). Of those who incorrectly reported results, it was more common for patients and care partners to report a negative scan result when the scan was actually positive for amyloid- β . Result concordance matrices broken out by level of cognitive impairment (MCI versus dementia) can also be found in Table 2. Patients with dementia and their care partners had higher rates of accurate reporting of results (86.3% and 88.7%, respectively) compared to patients with MCI and their care partners (81.2% and 83.5%, respectively), $\chi^2(2, N = 1,845) = 5.58, p = 0.018$ for patients and $\chi^2(2, N = 1,845) = 7.56, p = 0.006$ for care partners.

In 75% of dyads, both patient and care partner correctly reported results, while in 7% of dyads, both incorrectly reported results (Table 3). The remaining 18% of dyads were discordant in their reporting of scan results.

Multivariate analysis results

In unadjusted results, a diagnosis of dementia versus MCI, lower patient TICS-M score, and higher care partners' CAPACITY Communication score were predictors of patients more accurately reporting scan results significant at the $p < 0.05$ level (Table 4). When controlling for all factors in the adjusted model, only patient TICS-M scores was a predictor of patient's report accuracy significant at the $p < 0.05$ level. On average, a one-point increase in a patient's TICS-M score was associated with a 0.4 percentage point decrease in the predicted probability of a patient accurately reporting his or her scan result (ME: -0.004 , 95% CI: $-0.007, -0.000$). A higher TICS-M score indicates higher cognitive function; thus, these results indicate patients' higher cognitive function was associated with a lower probability of patients accurately reporting results.

In the analysis of care partner report concordance, unadjusted models show the patient having dementia compared to MCI, lower patient TICS-M score, higher care partner TICS-M, and higher care partner CAPACITY Communication scores were predictors of care partners more accurately reporting scan results significant at least at the $p < 0.05$ level (Table 5). When controlling for all factors in the adjusted model, patients' TICS-M score and care partners' CAPACITY Communication score were significant predictors of care partner report concordance. Similar to the patient report concordance model, a higher patient TICS-M score—higher patient cognitive function—was associated with a lower probability of care partners accurately reporting results. Additionally, care partners' CAPACITY Communication score was a positive predictor of care partners accurately reporting results. On average, a one-point increase in a patient's TICS-M score was associated with a 0.4

percentage point decrease in the predicted probability of the care partner accurately reporting the patient's scan result (ME: -0.004 , 95% CI: -0.007 , -0.001). A one-point increase in a care partner's CAPACITY Communication score was associated with a 3.4 percentage point increase in the predicted probability of a care partner accurately reporting the patient's scan result (ME: 0.036 , 95% CI: 0.01 – 0.06).

Analyzing the outcome of dyadic concordance, when controlling for confounding factors, patients' TICS-M score was negatively associated with dyadic concordance. In other words, a patient's higher cognitive function was associated with a lower predicted probability of dyadic concordance (Table 5). On average, a one-point increase in a patient's TICS-M score was associated with a 0.4 percentage point decrease in the predicted probability of dyadic concordance (ME: -0.004 , 95% CI: -0.007 , -0.001). Additionally, patients having obtained higher than a high school degree was associated with a lower predicted probability of dyadic concordance compared to those patients with a high school degree or less education.

Qualitative results

Patients and care partners who answered open-ended questions offered a range of depth of interpretation of the scan results, with some reporting "That I do have the disease, and they're sure of that.", while others explained how the information had been relayed to them by a medical professional and the expected disease prognosis. Their answers offer important insight into the potential sources of misunderstanding when reporting scan results. Of the 202 transcribed dyad surveys, 37 patients and 26 care partners had incorrectly reported scan results in the survey questionnaire. Three consistent themes that emerged were errors due to cognitive impairment, confusion with diagnostic terminology, and ambiguous diagnosis and prognosis. Those who reported the scan results incorrectly exhibited both signs of cognitive impairment particularly in patients who had progressed to dementia, as can be expected, but also confusion about diagnostic terminology for both patients and care partners. For example, one care partner interpreted a positive scan result: "According to the doctor, it was going to show whether or not he has Alzheimer's. And it came out positive that he does not". There were also instances where patients and care partners inaccurately reported results (e.g., reported negative when the scan was positive for amyloid), but their open-ended response was closer to an accurate understanding of the scan result and prognosis. For example, a care partner who reported "negative scan" when the scan was positive for amyloid- β , responded, "[T]here's a progression of the plaque in her brain, from the six months prior, to that PET scan." The responses from those who correctly reported the results tended to suggest less confusion with the diagnostic terminology. However, at least one care partner after correctly reporting a positive scan still appeared to confuse the terminology when responding, "... when I said the PET scan was positive, it was positive for us. [the physician] didn't see anything on the PET scan ..."

Additionally, among those with incorrect reporting on the survey, many patients with MCI and their care partners mentioned that the physician did not provide them with a clear diagnosis as a result of the amyloid- β PET scan. One patient reported that "it means there is potential for future Alzheimer's or other dementia", which, although an accurate way of communicating a positive amyloid- β PET scan to a patient with MCI, may also cast doubt

about whether the actual scan results were positive or negative in the mind of patients and care partners. Finally, some care partners reported not being present at the medical visit, which would directly impact their ability to correctly report these results: “I was not there for the results. She went by herself”.

DISCUSSION

This study sought to describe rates of patient and care partner accurate reporting of results and the concordance within dyads of accurate reporting, determine predictive factors of patients and their care partners reporting results and the concordance between those results, and finally, provide qualitative insights into patient and care partners’ interpretations. Overall, there were high rates of accurate reporting with patients with dementia and their care partners having higher rates of accurate reporting (86.3% and 88.7%, respectively) compared to patients with MCI and their care partners (81.2% and 83.5%, respectively). A consistent finding across regression analyses when controlling for patient and care partner confounding factors is an inverse relationship between patients’ cognitive function, as measured by the TICS-M score, and correct report of results. Qualitative insights provided further illumination that many of those who inaccurately reported results also appeared to struggle with diagnostic terminology and a lack of clear reporting from their provider.

These quantitative and qualitative findings are consistent with the literature that shows those with MCI—those with less severe cognitive impairment and those with higher TICS-M scores on average—are not going to receive as definitive prognoses or diagnoses as compared to those with dementia and thus may have a harder time accurately reporting results [10, 12]. Importantly, both patients with MCI and their care partners were less accurate in their scan results reporting compared to dyads where the patient had dementia. This consistency between patients and their care partners pattern of inaccurate reporting suggests that it is not the patient’s cognitive impairment that is driving inaccurate reporting, but rather, it may be related to the exchange of information regarding the patient’s diagnosis and prognosis or possibly the relevance placed on the results. Patients’ cognitive status, as measured by the TICS-M measure, was also predictive of dyadic concordance, which further suggests that there is a greater confusion among dyads where the patients had a higher cognitive status.

Despite the fact that the survey question spelled out the meaning of positive (amyloid- β plaque present) and negative (amyloid- β plaque absent) results, this terminology can be difficult to grasp for a lay audience that may persist with a view of “positive” results as good news. There was also confusion about the difference between the diagnostic categories of mild cognitive impairment versus dementia, as compared with the differential diagnoses that the scan results could potentially inform (e.g., Alzheimer’s disease, Lewy body dementia, etc.). Patients with MCI and their care partners’ responses about ambiguous diagnosis and prognosis reflect the potential difficulty in understanding a positive amyloid- β scan in light of the uncertain progression of the disease.

Clinical practice implications

It is important that both patients and care partners can accurately report results as a first step in understanding results and enabling shared decision-making. Shared decision-making—a partnership between patients and clinicians where patients' values and preferences as well as the best medical evidence are considered [25]—is a critical component of high quality care, and only possible when the patients understand their diagnosis and prognosis. Particularly for patients with MCI, care partners play an important role in making decisions as they can learn patients' values and preferences and use this knowledge to be the patients' proxy when the patients' cognitive function declines [13, 26]. However, while patients with MCI may have the greatest opportunity to benefit from shared decision making, it should be acknowledged that promoting shared decision making in these circumstances may be the most challenging given the high ambiguity associated with the result of the amyloid PET scan and prognosis in this population.

The nuances of etiology and prognosis of cognitive impairment, especially for MCI patients, present unique communication challenges for providers. Recommendations for how providers communicate amyloid- β PET scan results to MCI patients include setting appropriate expectations especially ensuring patients and care partners understand the limitations of amyloid- β imaging [10]. Additionally, these recommendations include being specific with MCI patients and their care partners that a negative scan result does not remove the elevated risk for dementia, and a positive result is also not definitive but should elicit further monitoring and conversations about advanced care planning. This study's findings demonstrating a negative relationship between patients' TICS-M scores and result concordance and dyadic concordance underscore the importance of ensuring both patients and care partners understand amyloid- β PET scan results especially when diagnosis and prognosis may not be as definitive.

Qualitative results emphasized the challenge of interpreting diagnostic terminology for patients and care partners, specifically understanding the meaning of positive and negative scan results. Understanding how patients and care partners comprehend this information is important given the clinical and ethical problems that can arise with misunderstanding [27]. Clinicians can learn from research protocols that have evaluated standardized multi-step procedures to disclose amyloid PET scan results to cognitively normal older adults [28]. Although different issues need to be addressed when providing results to cognitively impaired individuals, standardized procedures and the use of terminology such as 'elevated' versus 'non-elevated' amyloid may minimize confusion and improve understanding of the results. Our study's findings demonstrate potential pitfalls of using confusing language and lack of protocolized amyloid PET scan result disclosure. Furthermore, our regression analyses indicate that for dyads where care partners had higher education levels there was a lower probability of patients and care partners being concordant in their responses, although this could be influenced by the sample composition being highly educated. These findings underscore the notion that even highly educated individuals struggle with diagnostic terminology, and clinicians should not underestimate the difficulty in understanding results for patients and care partners of all educational backgrounds.

Limitations

One of the limitations of this study was the homogenous sample predominately consisting of white, highly educated male patients and white, highly educated female spousal care partners. We caution generalization to other populations. Another potential weakness of this study is the possibility of contamination of patient interviews where care partners of patients with more severe cognitive impairment may have been more likely to help patients answer questions when the patient seemed to struggle with answers. While we have no evidence this interference took place, if it did, it would bias our regression results towards zero since cognitive impairment was negatively associated with accurate reporting. Additionally, although providers watched a training video on best practice recommendations for disclosing amyloid PET results, there were no standard procedures for disclosing scan results to patients and their care partners. Thus, it is uncertain the terminology used by providers (e.g., positive/negative versus elevated/not elevated) and the level of certainty conveyed in communicating the presence of amyloid- β . This lack of standardization may have also disproportionately contributed to the confusion among dyads where the patient had MCI compared to dyads where the patient had dementia, due to the ambiguity of the prognostic interpretation of the scan results in MCI. A concern regarding our analyses was that while we found significant differences in accurate reporting among patients and care partners based on MCI versus dementia diagnosis, MCI versus dementia was not a significant predictor of accuracy in our adjusted models. We think the lack of significance of the MCI versus dementia variable in adjusted analyses is due to the variation being explained by the TICS-M variable. Finally, it is also important to note that this study could have been limited by a “ceiling” in rates of accurate reporting of scan results given that many adults, even the highly educated, struggle with interpreting probabilities and can misinterpret diagnostic terminology. This ceiling effect would mean that the variation in our outcome—correct report of results—is not explained by our explanatory variables, but rather, our outcome was representative of the highest percentage of correct reporting that can be found and therefore lacks variation.

Conclusion

This study of 1,845 patients with MCI or dementia and their care partners demonstrated an overall relatively high rate of accurate reporting of amyloid- β PET scan results among patients and their care partners and offered insights from a subsample of those patient and care partners into the difficulty of understanding the results. Additionally, this study found an inverse relationship between patients’ cognitive function and result concordance and dyadic concordance. These results reinforce the importance of provider communication and patient and care partner education, particularly in cases where the patient has MCI, to ensure patients and their care partners can correctly report the results of amyloid- β PET scans and ultimately better understand the results.

ACKNOWLEDGMENTS

The authors acknowledge Faye Dvorchak and Kathleen Nye for their support in managing the CARE-IDEAS study. Research reported in this publication was supported by National Institute on Aging, NIH, 1R56AG053934-01 and National Institute on Aging, NIH, 5R01AG053934-02. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. We have deposited specific

information regarding Stata code used in the analyses in an electronic repository as a guide for investigators who obtain the requisite data use agreement for the relevant data sources and want to replicate our study (<https://doi.org/10.26300/8ptw-5115>).

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Table 1

Characteristics of care partners and patients (by level of cognitive impairment)

Variable	Care partners	MCI patients	Dementia patients	* <i>p</i>
N	1845	1349	496	
Abbreviated TICS-M score, Mean (SD)	27.9 (5.0)	22.0 (5.7)	16.6 (6.0)	<0.001
Male	594 (32.2%)	816 (60.5%)	297 (59.9%)	0.81
Caucasian	1770 (95.9%)	1301 (96.4%)	475 (95.8%)	0.5
Age, Mean (SD)	70.1 (9.6)	74.6 (5.5)	74.6 (5.8)	0.95
Education				<0.001
High school graduate or less	260 (14.1%)	185 (13.7%)	104 (21.0%)	
Some college	514 (27.9%)	334 (24.8%)	125 (25.2%)	
Bachelor's degree	502 (27.2%)	338 (25.1%)	90 (18.1%)	
Graduate degree	569 (30.8%)	492 (36.5%)	177 (35.7%)	
Health literacy (1 = always need help reading hospital materials, 5 = never need help)				<0.001
1	37 (2.0%)	165 (12.2%)	124 (25.0%)	
2	43 (2.3%)	161 (11.9%)	78 (15.7%)	
3	122 (6.6%)	185 (13.7%)	72 (14.5%)	
4	315 (17.1%)	298 (22.1%)	84 (16.9%)	
5	1328 (72.0%)	540 (40.0%)	138 (27.8%)	
Relationship of care partner to patient				
Spouse/Significant Other	1630 (88.3%)			
Other	215 (11.7%)			
CAPACITY Communication score, Mean (SD)	3.1 (0.7)	—	—	

* *p* is comparing dementia to MCI patients.

TICS-M, Telephone Interview Cognitive Status-Modified; SD, standard deviation; MCI, mild cognitive impairment.

Table 2

Patient and care partner result concordance

Self-report of scan	Amyloid PET Scan Result		Correct reporting of scan results
	Positive for cortical amyloid- β	Negative for cortical amyloid- β	
All dyads (<i>n</i> = 1845)			
Patient			
Positive result	1072 58.1%	117 6.3%	1529 (82.9%)
Negative result	199 10.8%	457 24.8%	
Care partner			
Positive result	1092 59.2%	99 5.4%	1567 (84.9%)
Negative result	179 9.7%	475 25.8%	
MCI dyads (<i>n</i> = 1349)			
Patient			
Positive result	731 54.2%	92 6.8%	1101 (81.2%)
Negative result	156 11.6%	370 27.43%	
Care partner			
Positive result	748 55.5%	83 6.2%	1127 (83.5%)
Negative result	139 10.3%	379 28.1%	
Dementia dyads (<i>n</i> = 496)			
Patient			
Positive result	341 68.8%	25 5.0%	428 (86.3%)
Negative result	43 8.67%	87 17.5%	
Care partner			
Positive result	344 69.4%	16 3.2%	440 (88.7%)
Negative result	40 7.74%	96 19.4%	

Table 3

Dyadic concordance

Care partner	Patient		Total
	Correct report of scan result	Incorrect report of scan result	
Correct report of scan result	1385 75.1%	182 9.9%	1567 84.9%
Incorrect report of scan result	144 7.8%	134 7.3%	278 15.1%
Total	1528 82.9%	316 17.1%	1845 100%

Table 4

Marginal effects (ME) of patient and care partner characteristics on patient and care partner accurate report of results

	Patient accurate report of result		Care partner accurate report of result	
	Unadjusted ME (95% CI)	Adjusted ME (95% CI)	Unadjusted ME (95% CI)	Adjusted ME (95% CI)
Impairment level of patient				
MCI	REF	REF	REF	REF
Dementia	0.05 (0.01, 0.08) *	0.02 (−0.02, 0.06)	0.05 (0.02, 0.09) *	0.02 (−0.03, 0.06)
Patient TICS-M	−0.004 (−0.007, −0.003) *	−0.004 (−0.007, −0.000) *	−0.006 (−0.009, −0.003) ***	−0.004 (−0.007, −0.001) **
Patient male	−0.04 (−0.12, 0.04)	−0.04 (−0.12, 0.04)	0.03 (−0.005, 0.06)	−0.01 (−0.08, 0.06)
Patient Caucasian	−0.07 (−0.15, 0.02)	−0.07 (−0.15, 0.02)	−0.07 (−0.13, 0.002)	−0.05 (−0.14, 0.03)
Patient age	0.0005 (−0.003, 0.004)	0.0 (−0.003, 0.003)	0.002 (−0.0008, 0.005)	0.002 (−0.001, 0.006)
Patient Education				
High school graduate or less	REF	REF	REF	REF
Some college	−0.02 (−0.07, 0.04)	−0.02 (−0.07, 0.04)	−0.4 (−0.09, 0.02)	−0.03 (−0.08, 0.03)
Bachelor's degree	−0.02 (−0.08, 0.04)	−0.02 (−0.08, 0.04)	−0.05 (−0.07, 0.04)	−0.01 (−0.07, 0.05)
Graduate degree	0.03 (−0.03, 0.08)	0.03 (−0.03, 0.08)	0.01 (−0.04, 0.06)	0.01 (−0.04, 0.06)
Patient health literacy				
(1) Always need help	REF	REF	REF	REF
2	−0.008 (−0.08, 0.06)	−0.008 (−0.08, 0.06)	−0.01 (−0.06, 0.04)	−0.006 (−0.07, 0.05)
3	−0.02 (−0.09, 0.04)	−0.02 (−0.09, 0.04)	−0.09 (−0.15, −0.03) **	−0.08 (−0.14, −0.01) *
4	−0.001 (−0.06, 0.06)	−0.001 (−0.06, 0.06)	−0.05 (−0.10, −0.001) *	−0.03 (−0.08, 0.03)
(5) Never need help	−0.007 (−0.05, 0.06)	−0.007 (−0.05, 0.06)	−0.08 (−0.12, −0.04)	−0.05 (−0.10, 0.003)
Age difference (patient minus care partner age)	0.001 (−0.001, 0.003)	−0.001 (−0.004, 0.002)	0.001 (−0.001, 0.003)	0.000 (−0.003, 0.003)
Care partner TICS-M	0.001 (−0.003, 0.004)	0.001 (−0.003, 0.004)	0.003 (0.003, 0.006) *	0.002 (−0.001, 0.005)
Care partner male	−0.04 (−0.12, 0.05)	−0.04 (−0.12, 0.05)	−0.04 (−0.08, −0.005)	−0.03 (−0.12, 0.04)
Care partner Caucasian	−0.02 (−0.08, 0.13)	0.04 (−0.08, 0.15)	−0.06 (−0.13, 0.008)	−0.04 (−0.13, 0.04)
Care partner education				
High school graduate or less	REF	REF	REF	REF
Some college	−0.03 (−0.09, 0.02)	−0.03 (−0.09, 0.02)	0.03 (−0.03, 0.08)	0.008 (−0.05, 0.06)
Bachelor's degree	0.01 (−0.05, 0.07)	0.01 (−0.05, 0.07)	0.07(0.02, 0.13) *	0.05 (−0.005, 0.11)

	Patient accurate report of result		Care partner accurate report of result	
	Unadjusted ME (95% CI)	Adjusted ME (95% CI)	Unadjusted ME (95% CI)	Adjusted ME (95% CI)
Graduate degree	-0.02 (-0.07, 0.04)	-0.02 (-0.07, 0.04)	0.04 (-0.02, 0.09)	0.007 (-0.05, 0.07)
Care Partner health literacy				
(1) Always need help	REF	REF	REF	REF
2	0.05 (-0.13, 0.24)	0.05 (-0.13, 0.24)	0.18 (0.002, 0.37)*	0.15 (-0.02, 0.31)
3	0.05 (-0.12, 0.21)	0.05 (-0.12, 0.21)	0.12 (-0.05, 0.29)	0.08 (-0.08, 0.23)
4	0.10 (-0.05, 0.25)	0.10 (-0.05, 0.25)	0.18 (0.02, 0.33)*	0.12 (-0.02, 0.26)
(5) Never need help	0.12 (-0.03, 0.26)	0.12 (-0.03, 0.26)	0.18 (0.03, 0.33)*	0.13 (-0.01, 0.27)
Care partner's relationship to patient				
Other	REF	REF	REF	REF
Spouse/significant other	-0.03 (-0.12, 0.05)	-0.03 (-0.12, 0.05)	-0.07 (-0.06, 0.04)	0.02 (-0.08, 0.01)
Care Partner's CAPACITY Communication Score	0.03 (0.001, 0.05)*	0.02 (-0.004, 0.05)	0.05 (0.02, 0.07)***	0.034 (0.01, 0.06)**

* $p < 0.05$;** $p < 0.01$;*** $p < 0.001$.

Table 5

Marginal effects (ME) of patient and care partner characteristics on dyadic concordance

	Unadjusted ME (95% CI)	Adjusted ME (95% CI)
Impairment level of patient		
MCI	REF	REF
Dementia	0.04 (−0.000, 0.08)	0.000 (−0.04, 0.04)
Patient TICS-M	−0.005 (−0.008, −0.002)***	−0.004 (−0.007, −0.001)*
Patient male	0.006 (−0.03, 0.04)	−0.04 (−0.11, 0.04)
Patient Caucasian	−0.06 (−0.14, 0.01)	−0.10 (−0.16, −0.03)**
Patient age	−0.0004 (−0.004, 0.003)	0.000 (−0.004, 0.003)
Patient Education		
High school graduate or less	REF	REF
Some college	0.06 (−0.11, −0.009)*	−0.05 (−0.11, −0.001)*
Bachelor's degree	−0.06 (−0.11, −0.004)*	−0.06 (−0.11, −0.003)*
Graduate degree	−0.07 (−0.11, −0.02)**	−0.07 (−0.12, −0.02)*
Patient health literacy		
(1) Always need help	REF	REF
2	−0.03 (−0.09, 0.03)	−0.2 (−0.09, 0.04)
3	−0.07 (−0.13, −0.005)*	−0.05 (−0.12, 0.01)
4	−0.06 (−0.11, 0.007)*	−0.04 (−0.10, 0.02)
(5) Never need help	−0.07 (−0.12, −0.02)**	−0.04 (−0.09, 0.02)
Age difference (patient minus care partner age)	−0.001 (−0.002, 0.001)	−0.003 (−0.006, 0.000)
Care partner TICS-M	0.003 (−0.0001, 0.006)	0.003 (−0.001, 0.006)
Care partner male	−0.03 (−0.07, 0.01)	−0.07 (−0.16, 0.009)
Care partner Caucasian	0.05 (−0.04, 0.15)	0.12 (−0.02, 0.23)
Care partner education		
High school graduate or less	REF	REF
Some college	−0.004 (−0.06, 0.05)	−0.000 (−0.06, 0.06)
Bachelor's degree	0.04 (−0.02, 0.09)	0.04 (−0.02, 0.1)
Graduate degree	−0.002 (−0.06, 0.06)	0.01 (−0.05, 0.08)

	Unadjusted ME (95% CI)	Adjusted ME (95% CI)
Care Partner health literacy		
(1) Always need help	REF	REF
2	-0.04 (-0.23, 0.16)	-0.04 (-0.22, 0.1)
3	0.04 (-0.12, 0.19)	0.02 (-0.13, 0.16)
4	0.03 (-0.11, 0.18)	0.007 (-0.13, 0.14)
(5) Never need help	0.08 (-0.06, 0.22)	0.05 (-0.08, 0.18)
Care partner's relationship to patient		
Other	REF	REF
Spouse/significant other	-0.01 (-0.06, 0.04)	-0.03 (-0.12, 0.05)
Care Partner's CAPACITY Communication Score	0.03 (0.004, 0.06)*	0.02 (-0.006, 0.05)

* $p < 0.05$;

** $p < 0.01$;

** $p < 0.001$.