
Knowledge of personal information and caregiver awareness in Alzheimer's disease

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Abstract

We assessed the ability of 73 patients with Alzheimer's disease (AD) to recall important personal information like their names, their caregivers' names, their addresses, and their telephone numbers. We also assessed their caregivers' awareness of their abilities. There was an association between the abilities of the patients and their Mini-Mental Status Examination (MMSE) scores, with the patients with the lowest MMSE scores making the most errors. Five to 10 percent of the mildest patients were unable to state their addresses and telephone numbers correctly. The caregivers of the patients with intermediate MMSE scores made the most errors in their predictions, with up to 50 percent being incorrect and up to 37 percent overestimating their patients' abilities. We concluded that AD patients lose their ability to provide personal information as their illness progresses. Caregivers of patients with MMSE ranging from 10 to 25 are the most likely to be unaware of their patients' impairment. These findings highlight safety concerns in AD.

Key words: Alzheimer's disease, caregivers, dementia, memory, safety

Introduction

Patients with Alzheimer's disease (AD) lose their

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ability to function in their everyday lives as their illness progresses. As suggested by other researchers,^{1,2} AD patients may be grouped into three functional stages. Those in the early stage begin to lose their instrumental activities of daily living (ADLs), such as being able to shop, cook, and handle finances. Those in the middle stage begin to need reminders to perform basic ADLs, such as grooming, feeding, and bathing. Finally, those in the late stage experience loss of their basic ADLs.

One aspect of the functioning of AD patients that has received relatively little attention is their ability to recall personal information like their names, their caregivers' names, or their addresses. At least three mental status tests for assessing dementia include such questions,³⁻⁵ and there has been previous investigation into the autobiographical memory of AD patients.^{6,7} To our knowledge, however, no previous AD research has focused on the patients' recall of important personal information. The patients' ability to state such information may affect their day-to-day functioning when communicating with others who may not know them and, of most importance, in times of emergency. As their other cognitive abilities decline with disease progression, one would expect this type of capability to decline as well.

Another issue in the study of functional capabilities is caregiver awareness. Does the caregiver know the capabilities of the patient? In many situations caregiver awareness may not be important, for the caregiver may not have high expectations of the patient, or the caregiver may allow the patient to handle tasks without concern for errors. On the other hand, particularly with regard to safety issues, if a caregiver overestimates the patient's capabilities a potentially hazardous situation could arise. For example, a caregiver may not be diligent in supervising the patient while outside the home, assuming the

Table 1. Questionnaire

1. What is your name? (First and last name required.)
2. Spell your name. (First and last name required.)
3. What is your [caregiver's] name? (First and last name required.) The examiner should substitute the caregiver's relationship in the brackets. For example, if the patient's caregiver is his wife, the question is "What is your wife's name?"
4. What is your address? (Street, street number, and city required.)
5. What is your telephone number? (Area code not required.)
6. If you were to become very ill, who is your doctor? (Correct last name required.)
Instructions: Inform the patient that this is a test to check his or her memory for important facts in case of an emergency. Further explanation may be provided if asked. Details in parentheses are required for the question to be answered correctly. The examiner should request the information in parentheses only if the patient does not provide the information with the initial query.

patient is able to provide accurate information to others if he or she were to wander or become lost.

There have been many previous studies investigating the caregivers' awareness of the functional⁸⁻¹⁰ and cognitive¹¹⁻¹³ abilities of the AD patient. We are not aware of any studies that have assessed the caregivers' awareness of their patients' knowledge of personal information, however.

The purpose of this study was to determine the prevalence of impairment in providing important personal information in our outpatient clinic AD population, if there may be an association between this prevalence and the severity of the patients' dementia as measured by the Mini-Mental Status Examination (MMSE),¹⁴ if the caregivers of our AD patients are aware of their patients' ability to provide important personal information, and if there may be an association between the level of awareness of the caregivers and the severity of cognitive impairment of the patients.

Methods

Approval for conducting this study was obtained from the Southern Illinois University School of Medicine Springfield Committee for Research Involving Human Subjects. Consent for participation was obtained from the caregivers and the patients.

Consecutive patient and caregiver pairs were recruited from the Southern Illinois University School of Medicine Memory and Aging Clinic as they presented for routine clinic follow-up. All patients had been diagnosed with probable AD or mild cognitive impairment

(MCI), consistent with current guidelines,^{15,16} assuming MCI represents an early stage of AD.¹⁶

To be included in this study, the caregiver must have been the primary caregiver, defined as the family member who assumed the most responsibility for overseeing the day-to-day functioning of the patient. All patients had an MMSE performed that day. Nursing home residents were excluded.

A questionnaire was used to determine if the patient was able to answer six basic personal information-related questions, presented in order of increasing difficulty (Table 1). The intent was to elicit autobiographical facts that could be important if the patient became lost or injured when the caregiver was not present. A matching worksheet was prepared that determined the caregiver's judgment of how the patient would answer each question.

The investigator first asked the caregiver if the patient could correctly answer each of the questions. The caregiver was not allowed to discuss any of the questions with the patient before answering. The investigator then administered the questionnaire to the patient. The caregiver was not allowed to assist the patient in any way. The answers were considered correct or incorrect, with no partial credit given. For the caregivers, a correct response was accurately predicting whether the patient's response for that question would be correct or incorrect. For example, if a caregiver predicted that the patient could not spell his name correctly (Question 2) but the patient then did spell it accurately, the caregiver's response was incorrect. The accuracy of the patients' responses was confirmed by comparing them with the medical record.

Table 2. Demographics of the participants

Patient group	Number in group	Gender (male/female)	Average age (years)	Average MMSE score	Number with spouse as caregiver	Number living by self
All patients	73	23/50	76.7	20.3	43	16
MMSE 26 to 30	20	7/13	75.6	26.9	14	4
MMSE 21 to 25	25	7/18	76.5	22.9	15	6
MMSE 16 to 20	13	3/10	77.5	18.0	6	5
MMSE 10 to 15	8	5/3	79.0	13.6	5	0
MMSE 0 to 9	7	1/6	76.3	4.4	3	1

MMSE, Mini-Mental Status Examination¹⁴ score.

Demographic information was also obtained, including age and gender of the patient and the caregiver and their family relationship. Whether the patient was living alone and the length of time the patient had had his or her current address and telephone number were also determined.

Statistical analysis was performed using GraphPad InStat version 3.01 for Windows 95 (GraphPad Software, San Diego, CA). Linear regression was used to assess the relationships between the percentage of patient correct responses in answering the questions and their MMSE scores and ages. Linear regression was also used to assess the relationships between the percentage of caregiver correct responses and their ages, and their patients' MMSE scores. Fisher's Exact Tests were used to compare the percentage of correct responses of the spouse caregivers with that of the nonspouse caregivers and to compare the percentage of correct responses of the patients and the caregivers with respect to their genders. Multiple regression analysis was used to assess possible interrelationships between patient and caregiver responses and their ages and patient MMSE scores.

For presentation of the data, the patient and caregiver pairs were divided into groups according to the patients' MMSE scores. MMSE groupings of 21 to 30, 11 to 20, and 0 to 10 were used, consistent with early-stage, mid-stage, and late-stage dementia, respectively, as suggested by other researchers.^{1,2} To provide better graphical discrimination, we subdivided the MMSE 11 to 20 and 21 to 30 groups into MMSE 11 to 15, 16 to 20, 21 to 25, and 26 to 30 subgroups.

Results

A total of 73 patient-caregiver pairs were recruited for

this study. Demographic information is presented in Table 2. The caregivers included 26 husbands, 20 daughters, 17 wives, five sons, three daughters-in-law, one sister, and one niece. No patient-caregiver pairs were excluded after consent was obtained. None were judged to have had difficulty answering the questions because of visual or hearing impairment.

The patient and caregiver responses for each question are presented in Figures 1 through 6. For each figure, the percentages of patients and caregivers with correct responses are plotted with respect to the MMSE scores of the patients. The percentage of caregivers with correct responses, excluding underestimation, is also plotted on each figure.

Question 1 (Figure 1): Stating their names

Two patients in the MMSE 0 to 9 group did not state their names correctly. One MMSE 3 patient gave her maiden name, and one MMSE 6 patient answered "yes" to the question, even after it was repeated several times. Three of the caregivers of this group were incorrect in predicting that their patients would be unable to state their names. All other patients and caregivers were correct.

Question 2 (Figure 2): Spelling their names

Only five patients did not spell their names correctly, four in the MMSE 0 to 9 group and one MMSE 16 patient. With the exception of one caregiver of an MMSE 6 patient and one of an MMSE 19 patient who underestimated their patients' responses, all of the caregivers were correct.

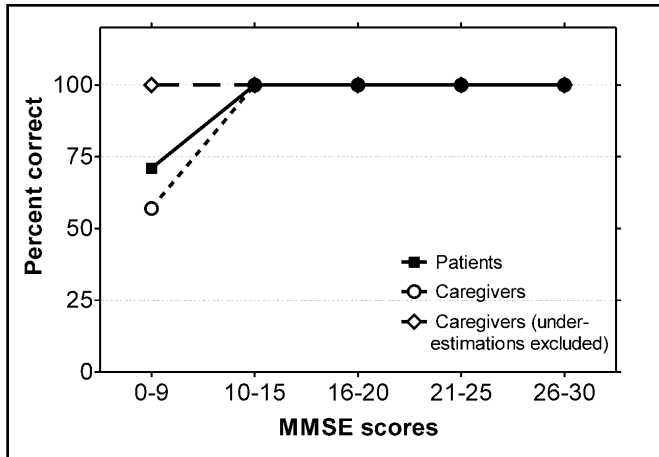


Figure 1. Prevalence of patients and caregivers answering Question 1 (stating their name) correctly.

Question 3 (Figure 3): Stating their caregivers' names

Three of the patients in the MMSE 0 to 9 group and one MMSE 17 patient did not state their caregivers' names. All other patients were correct. Five caregivers were incorrect in their predictions (MMSE of 4, 6, 12, 16, and 17).

Stating and spelling their names and stating their caregivers' names were the easiest questions for the patients to answer. With the two exceptions mentioned above, every patient with an MMSE score greater than 6 correctly answered these questions. These were also the three questions the caregivers predicted most accurately.

Question 4 (Figure 4): Stating their addresses

There were patients in every MMSE group who did not state their current addresses correctly, including two in the mildest group (MMSE 26 and 27). Ten of 13 (77 percent) in the MMSE 16 to 20 group, five of eight (62 percent) in the MMSE 10 to 15 group, and all in the MMSE 0 to 9 group were incorrect. Whereas the caregivers of the most severe and most mild groups were almost completely aware of their patients' capabilities in this regard, those in the three intermediate groups were 20 to 50 percent incorrect, with 16 to 37 percent of the predictions being overestimations.

The patients had been living at their addresses for an average of 24.9 years, ranging from seven weeks to 60 years. In general, those who had been living at their current addresses for the shortest times had the most difficulty. For example, six of the seven who had been living at their addresses for less than one year were unable to state their addresses correctly (mean MMSE 16.8, range 4 to 24). On the other hand, many of those with relatively

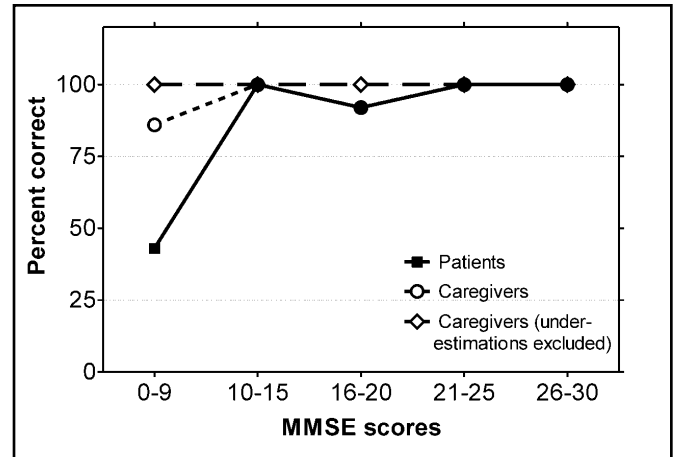


Figure 2. Prevalence of patients and caregivers answering Question 2 (spelling their name) correctly.

high MMSE scores who had been living at their current addresses for at least 20 years were also unable to state their correct address. For example, six of eight in the MMSE 16 to 20 group were unable to answer this question.

Question 5 (Figure 5): Stating their telephone numbers

Similar to Question 4, there were patients in every MMSE group who did not state their current telephone numbers correctly, including one MMSE 27 patient. Six of 13 (46 percent) in the MMSE 16 to 20 group, seven of eight (87 percent) in the MMSE 10 to 15 group, and all in the MMSE 0 to 9 group were incorrect. As with Question 4, the caregivers in the three intermediate groups were the most unaware of their patients' capabilities, with 20 to 31 percent being incorrect, 8 to 25 percent being overestimations.

The patients had had their current telephone numbers for an average of 24.3 years, ranging from one week to 60 years. Similar to Question 4, those who had had their telephone numbers for the shortest times tended to have the most difficulty. For example, seven of the eight who had had their telephone numbers for less than one year did not state their current telephone numbers correctly (mean MMSE 17.8, range 4 to 24). Also similar to Question 4, many of those with relatively high MMSE scores who had had their telephone numbers for at least 20 years were also incorrect. For example, three of eight in the MMSE 16 to 20 group were unable to answer the question correctly.

Question 6 (Figure 6): Stating their primary physicians' names

The results of this question were also very similar to

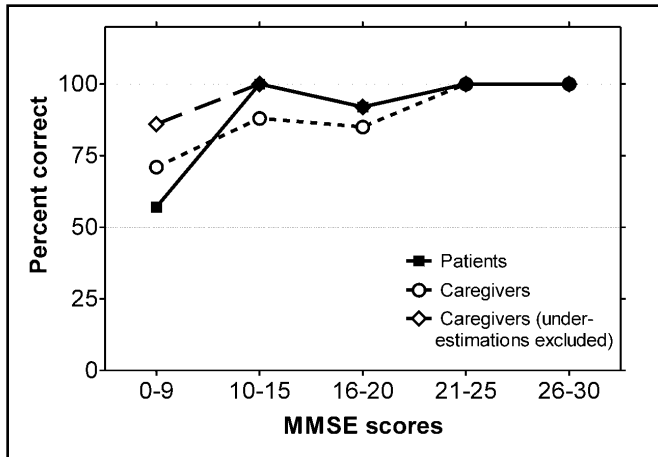


Figure 3. Prevalence of patients and caregivers answering Question 3 (stating their caregiver's name) correctly.

those of Question 4. With lower MMSE scores there was a greater prevalence of patients who had difficulty, ranging from two of 20 (10 percent) in the MMSE 26 to 30 group to all of those in the MMSE 0 to 9 group. A similar trend as in Question 4 was also seen for the caregivers, with those of the highest- and lowest-scoring groups being the most accurate in their predictions, and those of the intermediate groups being from 25 to 44 percent incorrect, 8 to 28 percent being overestimations.

For each of the six questions there was a significant linear relationship between the patients' MMSE scores and the percentage of correct patient responses ($r = 0.46$ to 0.65 , $p < 0.001$), with lower MMSE scores predicting a lower percentage. Considering other possible linear relationships, the percentage of correct caregiver responses was only associated with patient MMSE scores for Questions 1 and 3, with lower MMSE scores predicting a lower percentage ($r = 0.48$, $p < 0.001$ and $r = 0.37$, $p = 0.0012$, respectively). There were no significant differences in percentage of correct responses between spouse and nonspouse caregivers or between genders of the patients or caregivers. For Question 4, greater patient age predicted a lower patient percentage ($r = -0.31$, $p = 0.0072$), independent of MMSE score.

Discussion

Our results confirmed that patients with AD lose their ability to provide important personal information as their other abilities also decline. Although we did not test the patients under true emergency conditions, this finding suggests that many AD patients would not be able to provide important information to ensure their return home if they became lost. Five of eight of the patients in the MMSE 10 to 15 group were unable to state their addresses,

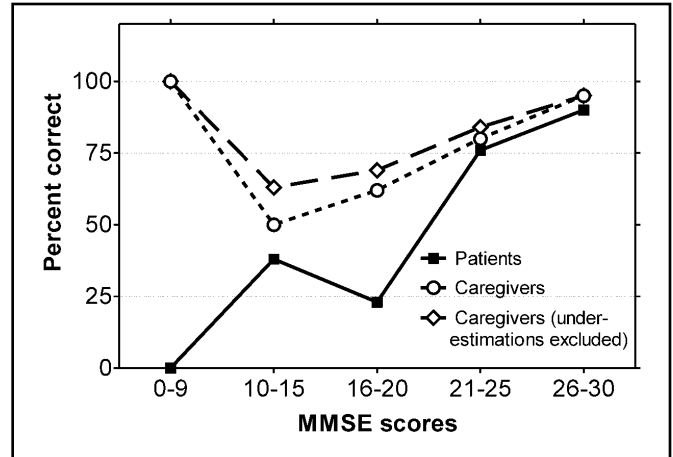


Figure 4. Prevalence of patients and caregivers answering Question 4 (stating their address) correctly.

and seven of eight were unable to state their telephone numbers. All of those with MMSE scores less than 10 were unable to state their addresses or telephone numbers, and four of seven were unable to spell their names correctly.

What was not expected in this study was that many patients with relatively high MMSE scores also had difficulty providing basic personal information. Sixteen to 28 percent of those in the MMSE 21 to 25 group and 5 to 10 percent of those in the MMSE 26 to 30 group were unable to state their addresses, their telephone numbers, or their physicians' names.

We also did not anticipate that so many caregivers would be unaware of their patients' shortcomings. Caregivers of the patients with MMSE scores in the intermediate groups (MMSEs 10 to 25) were the most inaccurate in their predictions, with up to 50 percent of them being incorrect regarding whether their patients could state their addresses. That caregivers make errors in judging the functional capabilities of their patients has been previously reported, however, as other studies have shown that caregivers may make underestimations and overestimations.^{8-10,17,18} For example, Arguelles and coworkers found that from 25 to 50 percent of caregivers incorrectly believed that the patient was able to tell time, count currency or make change for a purchase, brush his or her teeth, or use eating utensils.¹⁸

It is interesting that the caregivers of the least-impaired patients and those of the most-impaired patients were the most accurate in predicting the responses of their patients for the more difficult questions. This resulted in an inverted bell-shaped curve for the caregivers' results in Figures 4, 5, and 6, with the caregivers of the MMSE groups 0 to 9 and 26 to 30 being more accurate than those of the intermediate

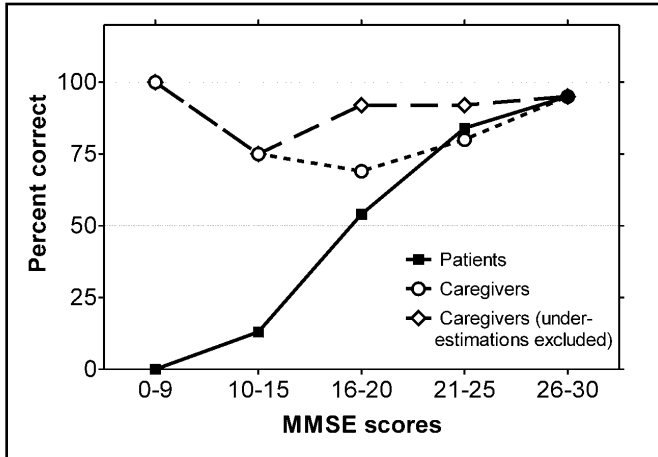


Figure 5. Prevalence of patients and caregivers answering Question 5 (stating their telephone number) correctly.

groups. A logical explanation for this may be that the caregivers of the least-impaired patients are accurate because their patients have not yet started to make errors, the caregivers of the intermediate patients make errors because their patients are increasingly making errors, and the caregivers of the most-impaired patients are again accurate because they have learned that their patients make many errors. We do not know of other studies reporting this inverted bell-shaped curve phenomenon.

An important detail in our study was the distinction between caregiver over- and underestimation. From the safety standpoint, an overestimation was clearly more significant, for it indicated that the caregiver incorrectly believed that the patient would be able to provide accurate personal information in an emergency situation. The most prominent example of this was our question asking the patients to state their addresses (Figure 4), for which 37 percent of the caregivers of the MMSE 10 to 15 group overestimated their patients' responses. Whereas we did not pursue reasons to explain the differences between caregiver over- and underestimation of their patient's abilities, other research groups have investigated contributing factors such as caregiver depression and perceived burden^{10,18} and patient education and severity of dementia.¹⁹

A limitation of this study is that we did not take into consideration any of the reported patient and caregiver biases that may have influenced the results. In addition to sociodemographic characteristics, these factors include patient and caregiver living arrangement, relationship, frequency of contact, depression, and educational history.^{10,13,17-20} Possible additional caregiver biases include perceived physical,

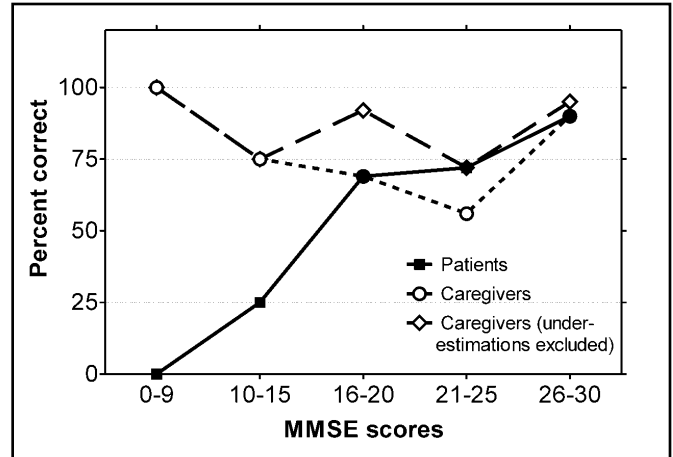


Figure 6. Prevalence of patients and caregivers answering Question 6 (stating their primary physician's name) correctly.

social, emotional, and time-dependence burden.^{8,17,18} Patient behavioral disturbances may also have biased our findings.^{8,17}

Our patients may have done better during "live" ("I am lost!") situations, or if the questions were asked in a more familiar environment, such as their homes.^{9,18} We also had a relatively small population of patient and caregiver pairs, and they were recruited from a clinic sample rather than a community population, with few patients in the more impaired groups. Nevertheless, whereas we do not doubt that more thorough questioning and a larger patient-caregiver base would have yielded more accurate results, it is unlikely that such considerations would have substantially altered our overall findings of increasing patient impairment and limited caregiver awareness as AD progresses.

Their names, the spelling of their names, their caregiver names, their addresses, their telephone numbers, and their physician names are very important personal details, yet our findings show that many AD patients become unable to provide this information accurately as their disease progresses. Moreover, our findings show that many caregivers are unaware of their patients' ability to state such personal information during the middle stage of AD. As a consequence, we believe caregivers and patients could benefit from education about such potential losses during the course of AD. Caregivers could be encouraged to review this type of information periodically with their patients, not only to help their patients remember it, but also to help the caregivers be more aware of potential losses. If nothing else, even relatively mild AD patients should carry identification with them when they are out of the home.

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