

# Do Alzheimer's Disease Patients Want to Participate in a Treatment Decision, and Would Their Caregivers Let Them?

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**Purpose:** This study was designed to examine the factors associated with the preferences of Alzheimer's disease patients to participate in a decision to use an Alzheimer's disease-slowing medication and how involved their caregivers would let them be in this decision. **Design and Methods:** Interviews were conducted with 48 patients in the mild-to-moderate stage of Alzheimer's disease and their caregivers. **Results:** Ninety-two percent of patients indicated they would participate in an Alzheimer's disease treatment decision, whereas 71% of caregivers thought the patient would participate. Half of the caregivers who indicated that their relatives would participate had relatives who did not have the capacity to make the decision based on a consensus of three expert psychiatrists. Patients' insight into their diagnosis and prognosis, and having less cognitive impairment, being a female caregiver, and being a spousal caregiver were all associated with the likelihood that the patient would participate in the treatment decision.

Patients talked about wanting to be involved in the process of making a treatment decision, whereas caregivers talked about assessing whether their relative could participate in the process of decision making. **Implications:** Mild-to-moderate stage Alzheimer's disease patients want to be involved in making treatment decisions, and caregivers are generally willing to involve them. Caregivers of Alzheimer's disease patients talk about patient participation in relation to elements of the capacity to make a treatment decision. Clinicians can provide guidance and education to assist caregivers in understanding how to assess their relatives' abilities to make decisions and navigate the decision-making process.

*Key Words:* Dementia, Decision making, Capacity, Patient participation

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As a result of cognitive impairments, patients with Alzheimer's disease may not have adequate decision-making capacity to give informed consent for medical treatments (Feinberg & Whitlatch, 2001; Karlawish, Casarett, Propert, James, & Clark, 2002; Marson & Harrell, 1999) that affect their ability to make a choice, understand, appreciate, and reason through the relevant information (Grisso & Applebaum, 1998a). As Alzheimer's disease progresses, these patients gradually require others, usually family members, to take on a greater role in assisting and ultimately taking over as the medical decision maker (Hirschman, Xie, Feudtner, & Karlawish, 2004). However, to our knowledge there are no published data that explain whether these patients would want to participate or whether their family members would let them participate in a decision to treat their dementia. Furthermore, it is unknown what factors (such as gender and relationship to patient) are associated with patient participation in a treatment decision.

Studies of persons with mild-to-moderate Alzheimer's disease have found that some patients in the mild-to-moderate stage, despite impairments in their cognitive abilities, have the capacity to participate in a treatment decision (Karlawish, Casarett, & James, 2002; Kim, Caine, Currier, Leibovici, & Ryan, 2001), and they are usually involved by their caregivers in general medical decisions (Karlawish, Casarett, Probert, et al., 2002). However, as dementia severity worsens, the capacity of individuals with Alzheimer's disease to make medical decisions declines; thus, their caregivers take on a greater role in making medical decisions for them. Therefore, a plausible relationship exists between a caregiver involving a patient in a treatment decision and the patient's capacity to make a decision about treating his or her Alzheimer's disease. Specifically, as dementia severity worsens or as a patient is judged to lack the capacity to make the decision, the caregiver is less likely to involve the patient in a medical treatment decision. Furthermore, given that involvement in a medical decision should be predicated on accepting that an individual has a problem that may benefit from treatment, it is plausible that a caregiver would involve his or her relative in an Alzheimer's disease treatment decision if the relative has some insight into his or her dementia.

In addition to losses in cognition, insight, and decision-making abilities, other characteristics of patients and their caregivers may influence whether the patient wants to be involved and whether his or her caregiver would involve the patient in a treatment decision. Older male patients tend to be more aggressive in making end-of-life treatment decisions, whereas female patients tend to want less treatment (Bookwala et al., 2001; Ditto et al., 2003). Older married couples tend to rely on each other when making decisions, often in a shared way (Padula, 1996). These data suggest that both the gender and the relationship between patient and caregiver may have an impact on the type of decision being made. It is plausible that gender and the relationship between the patient and caregiver may have an influence on the process of decision making. However, little is known about whether gender or spousal relationship influences how decisions are made when one half of the dyad is impaired by dementia. Furthermore, there are neither published data that examine why Alzheimer's disease patients would or would not want to participate in treatment decisions that affect their medical care, nor any research on the process of how caregivers of Alzheimer's disease patients decide to involve their relative in a treatment decision.

The present study is drawn from a larger research study investigating the capacity of patients with Alzheimer's disease to make a treatment decision and caregivers' preferences for the use of Alzheimer's disease treatments (Karlawish, Casarett, James, et al., 2003; Karlawish, Casarett, James, Xie, & Kim, in press). Our goals in this study were (a) to

assess patients' preferences to participate in a decision to use an Alzheimer's disease-slowing treatment; (b) to assess how involved their caregivers think that the patients would be in participating in the decision; (c) to identify patient and caregiver characteristics associated with caregivers' reporting that their relatives would participate; and (d) to explore how patients and caregivers discuss the process of patient participation in making an Alzheimer's disease treatment decision.

## Methods

### Participants

We recruited 48 patient-caregiver dyads from the Memory Disorders Clinic of the Alzheimer's Disease Center at the University of Pennsylvania to participate in face-to-face, in-home, audiotaped interviews. All patients had a diagnosis of possible or probable Alzheimer's disease as defined by NINCDS-ADRDA criteria (McKhann et al., 1984) and had mild-to-moderate Alzheimer's disease as measured by a Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975) score greater than 11 at their last clinic visit. Caregivers were eligible if they indicated they were involved in making decisions either with or for the patient. Patients and caregivers were interviewed separately at a convenient location.

### Alzheimer's Disease Treatment Decision Description

Appendix A shows the description of a medication that slows the progression of dementia that an interviewer read to the participants (Karlawish, Casarett, James, et al., 2003). This hypothetical medication was based on the risks and benefits measured in the Alzheimer's Disease Cooperative Study of vitamin E and selegiline in the treatment of Alzheimer's disease (Sano et al., 1997) and research showing that caregivers value and readily understand these risks and benefits (Karlawish, Klocinski, Merz, Clark, & Asch, 2000). The interviewer used the terms *dementia* and *memory loss* rather than *Alzheimer's disease* in order to limit any possible distress to the patients from using the term.

### Interview Design

A semistructured interview schedule with both open- and closed-ended questions guided the interviewers. First, the MacArthur Competency Assessment Tool for Treatment (MacCAT-T; see Grisso & Applebaum, 1998b) was completed (these data have been presented elsewhere; see Karlawish, Casarett, James, Xie, & Kim, in press). We used the MacCAT-T to assess the patient's capacity to participate in a decision to accept or refuse the Alzheimer's disease

treatment. Next, the interviewer asked all patients, "Would you participate in the decision whether you would take this medication?" (yes = 1, no = 0), and the interviewer asked caregivers, "Would your [relative] participate in the decision whether [he or she] would take this medication?" (yes = 1, no = 0). We defined participation as being a part of the discussion and final choice regarding the Alzheimer's disease treatment. Where appropriate, the research assistant performing the interview asked additional questions to elicit a clearer understanding of the patient and caregiver responses. For example, when respondents indicated no participation, they were asked, "Can you tell me why you said that?" If caregivers responded that the patient would participate in the treatment decision, caregivers were asked, "How much would the patient be involved in the decision in comparison with others?" We grouped these data into an ordinal variable, based on caregivers' answers to these questions, (response options were: the patient was not involved = 0, involved but less than others = 1, involved the same amount as others = 2, and more involved than others = 3) and a nominal variable (not involved = 0, involved = 1).

**Patient Insight.**—One component of measuring a patient's decisional capacity is to assess his or her appreciation (Grisso & Applebaum, 1998a), which includes a patient's insight into the disorder. This means recognizing the cognitive problems, diagnosis, and prognosis. The interviewer asked patients an open-ended question at the beginning of the interview about their health problems, including insight into their cognitive problems ("Do you have problems with your memory or thinking?"), prognosis ("Will your memory or thinking problems get worse?"), and diagnosis ("Do you have dementia or Alzheimer's disease?"). If patients responded "no" to the diagnosis question, the interviewer followed with the question, "What about a little bit of Alzheimer's disease or dementia?" (If patients responded "yes," the interviewer scored this as 1, and if "no," as 0) For patients who answered "no" to the symptoms question, the interviewer automatically scored the responses as 0 for prognosis because the follow-up prognosis question depended on the patient's acknowledgment of memory or thinking problems.

**Measurement of Patient Capacity.**—Three psychiatrists, with at least 5 years of postfellowship experience in capacity assessment, independently listened to the audiotaped patient MacCAT-T portions of the interviews. The psychiatrists assessed the patient's understanding (knowing the meaning of the treatment's benefits, risks, and purpose), appreciation (recognizing how treatment risks and benefits apply to the person), reasoning (comparing and describing personal consequences of the treatment to

the person), and ability to choose (deciding whether to take the treatment). Next the psychiatrists answered this question: "Based on your review of the tape you just listened to, does this person have sufficient capacity to give an informed consent to take or not to take this medicine?" Answer options were (a) definitely has sufficient capacity, (b) probably has sufficient capacity, (c) probably does not have sufficient capacity, and (d) definitely does not have sufficient capacity. We collapsed these codes into a dichotomous variable for capacity (0 = answer option a or b; 1 = answer option c or d). The expert reviewers did not know the following: participants' scores on measures of decision-making ability, insight, or cognition. They had no contact with the participants prior to the study. We defined whether the patient had the capacity to participate in the treatment decision or not by using the consensus of at least two raters' capacity judgments (Kim et al., 2001). Agreement among the three experts was  $\kappa = 0.50$  ( $\kappa = 0.20$ – $0.40$  indicates fair agreement and  $\kappa = 0.41$ – $0.60$  indicates moderate agreement; see Landis & Koch, 1977).

**Dementia Severity.**—We assessed dementia severity by using the MMSE score (Folstein et al., 1975), an 11-item scale widely used to assess overall cognitive function (score range, 0–30). Standard cut points used to define Alzheimer's disease severity are mild (MMSE  $\geq 20$ ), moderate (MMSE 19–12), and severe (MMSE  $< 12$ ).

**Depression and Caregiver Burden.**—We measured patient and caregiver depressive symptoms by using the 15-item Geriatric Depression Scale (GDS; Yesavage et al., 1983), in which a score greater than 5 defined depression. We measured caregiver burden by using the Screen for Caregiver Burden (SCB; Vitaliano, Russo, Young, Becker, & Maiuro, 1991), a 25-item instrument that asks caregivers to identify the occurrence and rate the level and severity of burden they experienced in the past 2 weeks. Both depression and burden are presented to describe the population.

**Patient and Caregiver Demographics.**—Demographic information on the patients' and caregivers' age, education, and race; patients' living situation; and caregivers' employment status, income, and relationship to patient are presented to describe the population.

## Analyses

A multidisciplinary panel, including a bioethicist (B. James), a sociologist (C. Joyce), and a physician (J. Karlawish) reviewed qualitative data. This multistep process began with the panel reviewing a sample of answers to the open-ended questions

**Table 1. Patient and Caregiver Characteristics**

Factor	Patients <sup>a</sup>	Caregivers <sup>a</sup>
Age, <i>M</i> ± <i>SD</i> (range)	78.7 ± 7.2 (63–96)	61.7 ± 13.9 (24–88)
Education, <i>M</i> ± <i>SD</i> (range)	14.3 ± 3.3 (8–20)	14.8 ± 2.8 (8–20)
Female, <i>n</i> (%)	29 (60.4)	34 (70.8)
White, <i>n</i> (%)	41 (85.4)	41 (85.4)
Patient residence, <i>n</i> (%)		
Alone or with caregiver or family member	41 (85.4)	
Nursing home or assisted living	7 (14.6)	
Relationship to patient, <i>n</i> (%)		
Spouse		23 (47.9)
Child (son, daughter, son-in-law, daughter-in-law)		22 (45.8)
Other		3 (6.3)
Employed (part & full time), <i>n</i> (%)		23 (47.9)
Income, <i>n</i> (%)		
\$0–\$29,999		9 (18.8)
\$30,000–\$69,999		16 (33.3)
≥ \$70,000		16 (33.3)
Missing		7 (14.6)

Notes: For the table, *N* = 48. Age and education are in years.

<sup>a</sup>Percentages may not add to 100 due to rounding.

regarding how involved the patient would be in making the Alzheimer's disease treatment decision, in order to develop preliminary codes based on themes that emerged from the answers. After the panel established a final set of codes, they recoded all interviews (Strauss & Corbin, 1990). Finally, the panel used QRS NUD\*IST software, a qualitative data-analysis program, (N6; QSR International Proprietary Limited, Melbourne, Australia) to facilitate the coding and the analyses process. The panel of coders resolved all disagreements through consensus agreement.

Second, we transferred the resulting categorization of the qualitative data into Stata statistical software (Intercooled Stata 8.0 for Windows, College Station, TX) along with patient and caregiver characteristics and patients' and caregivers' perceptions of patient involvement in the decision. Basic frequencies and appropriate nonparametric tests and tests of agreement are presented, as well as textual quotes to describe the decision-making processes. All tests were two sided.

### Human Subjects' Protections

The University of Pennsylvania Institutional Review Board approved this research. Patients provided verbal informed consent or assent and caregivers

provided informed consent to participate. Providing consent meant the patient was willing to participate and understood that the project was research, what the procedures were, and that he or she could drop out. Providing assent meant that the patient understood that the project was research and he or she was willing to participate.

## Results

In the original study, 102 (60%) out of 171 eligible patient-caregiver dyads agreed to participate (Karlawish, Casarett, James, et al., 2003). The main reason stated for not participating was lack of time. There were no demographic differences between refusers' and participants' race, relationship, or age. Of the 102 patients, all 48 of the mild-to-moderate Alzheimer's disease patients (47%) participated in an interview.

### Patient and Caregiver Characteristics

Table 1 shows patient and caregiver demographics. Male patients (17/19, 89.5%) were more likely than female patients (6/29, 20.7%) to be cared for by a spouse (Fisher's exact test, *p* < .001). This difference remained even when we adjusted for dementia severity.

### Patient and Caregiver Clinical Information

Table 2 shows patient and caregiver clinical information. One third to one half of the patients had some insight into their disorder (recognizing cognitive problems, 25/48, or 52.1%; diagnosis, 16/48, or 33.3%; and prognosis, 25/48, or 52.1%). The consensus of the three expert raters found that 40% (19/48) of the patients had the capacity to make a decision to use the Alzheimer's disease treatment.

### Do Patients Want to Participate in an Alzheimer's Disease Treatment Decision?

Almost all of the patients (44/48; 91.7%) said they would want to participate in an Alzheimer's disease treatment decision. The four patients who indicated they would not participate in making a treatment decision had lower MMSE scores (11, 15, 15, and 16) than did patients who said they would participate in the decision (MMSE, *M* ± *SD*, 20.9 ± 4.6; range, 12–29).

### Do Caregivers Think the Patient Would Want to be Involved in an Alzheimer's Disease Treatment Decision?

Caregivers' ratings of the degree of patient involvement in a treatment decision varied along a continuum: 29.2% (14/48) indicated that the patient would not participate; 27.1% (13/48) in-

icated that the patient would participate but would be less involved than others in the decision-making process; 22.9% (11/48) said that the patient's involvement would be the same as the caregiver, that is, a shared process; and 20.8% (10/48) said that the patient would be more involved than the caregiver in making a treatment decision.

### Factors Associated With Patient Participation

Given that nearly all patients wanted to participate in the decision to take the medicine, comparisons and interpretation of characteristics associated with wanting to be involved are limited. Analyses of the caregivers' answers to whether a patient would be involved in the decision showed that, as patient dementia severity increased, so did the likelihood that the caregiver was more involved than the patient in making a treatment decision (Spearman  $\rho = .379$ ;  $p = .008$ ). If the patient had insight into his or her prognosis (rank sum,  $p = .02$ ) and diagnosis (rank sum,  $p = .006$ ) and had the capacity to make a treatment decision (rank sum,  $p = .001$ ), caregivers said that the patient would be increasingly more involved in the Alzheimer's disease treatment decision. This finding suggests that caregivers are taking into account not only their relatives' dementia severity but also their relatives' insight into their condition, which is one component in determining whether an Alzheimer's disease patient has adequate ability to make decisions alone.

When we collapsed caregivers' responses into a dichotomous variable (1 = patient would participate on some level; 0 = patient would not participate at all), we found that caregivers were more likely to say that they thought their relatives would participate in making the treatment decision if the caregiver was female (28/34 women, or 82.4%, vs. 6/14 men, or 42.9%; Fisher's exact test,  $p = .01$ ), the caregiver was the spouse (21/23 spouses, or 91.3%, vs. 13/25 nonspouses, or 52.0%; Fisher's exact test,  $p = .004$ ), or the patient was male (18/19 men, or 94.7%, vs. 16/29 women, or 55.2%; Fisher's exact test,  $p = .003$ ). Female caregivers who were spouses (17/17 female spouses, or 100%) were more likely to involve the patient than female caregivers who were not spouses (6/17 female nonspousal caregivers, or 32.3%). No other patient or caregiver characteristics were associated with whether caregivers think their relative would participate in a treatment decision.

### What do Patients Think About Participating in Making an Alzheimer's Disease Treatment Decision?

Patients were asked to elaborate why they would or would not participate in the treatment decision. Of the four patients who said they would not

**Table 2. Patient and Caregiver Clinical Information**

Factor	Patients <sup>a</sup>	Caregivers <sup>a</sup>
MMSE score, $M \pm SD$ (range)	20.4 $\pm$ 4.8 (11–29)	28.8 $\pm$ 2.1 (21–30)
Dementia Severity, $n$ (%)		
Mild (> 19)	29 (60.4)	48 (100)
Moderate (12–19)	18 (37.5)	0
Severe (< 12)	1 (2.1)	0
GDS score, $M \pm SD$ (range)	2.3 $\pm$ 2.3 (0–8)	2.5 $\pm$ 2.6 (0–12)
Depressed, GDS > 5, $n$ (%)	6 (12.5)	9 (18.8)
Not depressed, GDS $\leq$ 5, $n$ (%)	42 (87.5)	39 (81.3)
SCB Subjective Burden, $M \pm SD$ (range)		33.7 $\pm$ 8.7 (25–61)
SCB Objective Burden, $M \pm SD$ (range)		7.9 $\pm$ 4.2 (2–9)

Notes: MMSE = Mini Mental State Examination; GDS = Geriatric Depression Scale; SCB = Screen for Caregiver Burden.

<sup>a</sup>Percentages may not add to 100 due to rounding.

participate, two patients said they did not trust themselves to make the decision (“I don’t trust my judgment”), one patient said, “If the doctor said I have to take [the medication]” she would leave the decision up to the doctor, and one patient did not think she had a problem “bad enough” to need to take a medication. The majority of Alzheimer's disease patients talked about the importance of being included in the decision process on some level (24/48, or 50%; e.g., “I’d like to have some say in what happens to me. I’d like to have a lot of say in what happens to me”; “If it involves me I would hope to”; “Would I? I jolly well better!”; and “I’d give my opinion”). Some patients talked about making the decision autonomously (5/48, or 10.4%; e.g., “Well of course I would participate in the decision. I would . . . participate, I would make the decision”; “I make my own decisions”).

### How do Caregivers Decide Whether an Alzheimer's Disease Patient Should be Involved in Making a Treatment Decision?

Caregivers' answers to an open-ended question asking them to explain why their relative would (34/48; 70.8%) or would not (14/48; 29.2%) participate in making an Alzheimer's disease treatment decision most frequently focused on whether the caregiver thought the patient had the capacity to participate (21/48; 43.8%). Caregivers described a process of assessing whether their relative could participate (e.g., Would be involved: “Well because I think that she still has enough cognitive and reasoning function to make that decision for herself”; Would not be involved: “I would say because his judgment isn’t right on these days, and he’s not able to weigh the

pros and cons, and you know, make rational decisions as he once did”). Among the caregivers who thought the patient would participate ( $n = 34$ ) in the decision, two additional common themes emerged: caregiver always involves the patient in decisions (14/34, or 41.2%; e.g., “Because she would want the input . . . especially my input, but the final decision would be hers”) and the patient would make his or her own decision (11/34, or 32.4%; e.g., “Because it’s his decision”; “I think she would listen to my opinion and her sister’s opinion but I think still the final decision would be hers”). Some caregivers, regardless of indicating that they thought the patient would (4/34; 11.8%) or would not (4/14; 28.6%) participate, stated that even though the patient would be involved in the discussion, the caregiver would be the one to make the final decision based on two themes: (a) the patient “trusts” or “relies” on the caregiver to make the decision, and (b) the caregiver is the decision maker in the dyad.

## Discussion

These results show that most patients with mild-to-moderate Alzheimer’s disease want to participate in the process of making a decision about treating their dementia, and that the majority of caregivers are in agreement with patient participation in the decision-making process. Caregivers justify patient participation in the treatment decision on the basis of their own assessment of the patient’s decision-making ability. Notably, we defined participation as being a part of the discussion and final choice regarding the Alzheimer’s disease treatment. However, some caregivers divided the patient’s role in the task. The patient participates in the treatment decision discussion, but the patient “trusts” or “relies” on the caregiver to make the final decision. Thus, the balance between patient autonomy and beneficence in decision making is not an either-or phenomena but rather a process that involves degrees of involvement in different parts of treatment decision making. Our results offer two specific findings that shed light on this process.

First, caregivers of patients with Alzheimer’s disease talk about the process that goes into deciding whether the patient should be included in medical decision making. Caregivers were able to identify that their relatives had a varied level of involvement in the decision, if involved at all. Not surprisingly, the severity of the patient’s dementia was associated with caregiver reports of patient involvement in a treatment decision. A caregiver was more likely to report greater involvement of the relative in making a treatment decision if the patient had insight into his or her prognosis and diagnosis and had the capacity to participate in the decision. These findings suggest that clinicians should encourage caregivers to talk with their relatives about their relatives’ diagnosis,

symptoms, and prognosis in order to identify when their relatives’ insight is impaired. The findings that participation was associated with patients’ capacity to make the decision and that caregivers evaluate the patients’ abilities to make a decision suggests that educating caregivers of Alzheimer’s disease patients in assessing their relatives’ ability to understand information may improve patient–caregiver communication and patient involvement in decision making. Although it is unreasonable to expect caregivers to formally assess their relatives’ decision-making capacity, their answers to our open-ended questions to explain why the patients would be involved suggest that they are using aspects of capacity assessment to determine whether to involve their relatives in decisions.

To assist caregivers, clinicians can discuss the changing roles of patient participation in decision making that occur as dementia progresses and how the caregiver’s roles change. These roles fit into three categories: (a) the patient has the capacity to make medical decisions, and the caregiver respects and supports the patient’s decisions; (b) the patient has a diminished capacity to make medical decisions, and the caregiver enters into the role of fostering shared or collaborative decision making and slowly transitions into a more vocal advocate and decision maker for the patient as capacity diminishes; and (c) the patient lacks the capacity to make medical decisions, so the caregiver makes final decisions but still informs the patient as much as possible about the decision and the process. In this study, patients were mostly in the middle stage of diminished capacity and caregivers talked about the need to include their relative, possibly as a symbolic inclusion, and at times make the final decision for their relative. The issue of patient involvement versus the caregiver’s comfort in having the patient make the final decision was not addressed by this study. These aspects of the decision-making process require further exploration.

Second, the caregiver’s gender and the caregiver’s relationship with the patient were associated with caregivers’ reporting that their relatives would want to be involved in treatment decisions. Female caregivers were more likely than male caregivers to indicate the patient would participate in the Alzheimer’s disease treatment decision. Furthermore, the data support that female caregivers who were spouses (17/17; 100%) were more likely to involve the patient (all of whom were male) than female caregivers who were not spouses (6/17; 32.3%). These results suggest not only that spousal caregivers may know the patient better than nonspousal caregivers and may be more likely to have had conversations about the patient’s health care preferences than nonspousal caregivers, but that female spousal caregivers may have closer relationships with their relative, may be more engaged with the person they care for, or may use different approaches to

communication with their relative than male spousal caregivers. These differences may originate in women's gender roles that suggest that decision making arises from patterns established and developed from relationship interactions (Chodorow, 1999; Gilligan, 1982; Markus & Osterman, 1989). The choices of female spouses may reflect a pattern of decision making engrained in the relationship between husband and wife (Robinson, 2000). Tangentially, these results are also similar to findings that support the use of a collaborative or shared decision-making process by women when making medical decisions (Degner et al., 1997; Padula, 1996). The question of how much these results reflect preexisting ways or gendered differences of making decisions for these dyads remains unanswered. For clinicians, there is an opportunity to help preserve patients' autonomy and desire to be involved in making decisions that affect their health, when possible, by making sure that nonspousal and male caregivers are encouraged to include patients in treatment decisions and that spouses and female caregivers are further educated about their relatives' impairments when unrealistic expectations of patient involvement are encountered.

Limitations of this study include that the decision to take the Alzheimer's disease-slowing treatment was about a hypothetical medication. Willingness to allow a patient to participate or a patient wanting to participate in a decision about a hypothetical treatment may not accurately reflect involvement or participation in an actual Alzheimer's disease treatment decision. However, we chose this approach because prior experience or views about the risks or benefits of current medicines would likely influence a discussion. An additional limitation of this study is the small sample size from one specific location, that is, an academic medical center's Alzheimer's Disease Center. Patients and caregivers who attend this type of clinic are unique in their understanding of Alzheimer's disease and their experience with health care professionals. Future studies should be designed to include more diverse patient-caregiver cohorts to assess involvement in treatment decisions. Finally, in this exploratory study there is the chance of a Type I error caused by the multiple comparisons.

The clinical implications of these data include that, when Alzheimer's disease patient-caregiver dyads make treatment decisions, practitioners can provide guidance, such as a handout containing information on the treatment options as a memory aid to assist the patient (Bourgeois, 1993) in making a decision as well as guide the caregiver in how to have the conversation with the patient. This would help the patient stay on task and assist the dyad in navigating the decision. Furthermore, both clinicians and caregivers need to examine the nature and extent of a patient's insight into his or her disease and how losses in insight impair a patient's capacity to make

and participate in the process of making a treatment decision. With caregivers playing a critical role in helping to make decisions for patients with Alzheimer's disease, it will continue to be important for health care professionals to explore how patient-caregiver dyads actually make these decisions and improve the process of decision making.

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## Appendix A: Description of Medicine to Slow Dementia and Memory Loss

I'd like you to imagine that your doctor has presented this treatment to you. The doctor explains that it is okay to take it with your other medications and that some people use it and some do not. The choice is yours. The medicine I will be talking about slows down dementia and memory loss. We know this because, for patients who use the medicine, new

symptoms or problems take longer to develop. So, for example, while it might take patients an average of 5 years before they need 24-hr nursing care, patients who use the medicine take 6 years before they need 24-hr nursing care. The medicine cannot bring back abilities the patient has lost. So, for example, if the patient cannot use a checkbook, taking the medicine won't make the patient able to do so. The medicine is taken once a day.

The following information is given to the subject after the above has been read out loud:

Benefits of the medicine: Slows down dementia and memory loss by 1 year:

- Patients live 1 year longer.
- There is a 1-year delay before needing 24-hr nursing care.
- There is a 1-year delay before developing problems recognizing family.

Risks of the medicine: An ulcer in the stomach or intestine that requires the patient to go to the hospital. The patient will likely need a transfusion. Surgery may be necessary to stop the bleeding. The chance of this risk is 3%. This means that if 100 people take it for 1 year, 3 of them will have this bleeding ulcer and 97 will not.