Neuropsychological Predictors of Decision-Making Capacity over 9 Months in Mild-to-Moderate Dementia

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BACKGROUND: Older adults with dementia may have diminished capacity to make medical treatment decisions.

OBJECTIVE: To examine rates and neuropsychological predictors of treatment decision making, or consent capacity, among older adults with dementia over 9 months.

DESIGN: Consent capacity was assessed initially and 9 months later in subjects with and without dementia using a longitudinal repeated measures design.

PARTICIPANTS: Fifty-three older adults with dementia and 53 similarly aged adults without dementia.

MEASUREMENTS: A standardized measure MacArthur Competence Assessment Tool-Treatment of 4 legal standards for capacity (Understanding, Appreciation, Reasoning, and Expressing a Choice) and a neuropsychological battery.

RESULTS: In the dementia group, 9.4% had impaired capacity initially, and 26.4% had impaired capacity at 9 months. Mean scores in the dementia group were impaired relative to controls initially and at 9 months for Understanding (initial $t=2.49$, $P=.01$; 9-month $t=3.22$, $P<.01$) and Reasoning (initial $t=2.18$, $P=.03$; 9-month $t=4.77$, $P<.01$). Declining capacity over 9 months was attributable to a further reduction in Reasoning (group $\times$ time $F=9.44$, $P=.003$). Discriminant function analysis revealed that initial scores on naming, delayed Logical Memory, and Trails B were associated with impaired capacity at 9 months.

CONCLUSIONS: Some patients with mild-to-moderate dementia develop a clinically relevant impairment of consent capacity within a year. Consent capacity in adults with mild-to-moderate dementia should be reassessed periodically to ensure that it is adequate for each specific informed consent situation. Interventions that maximize Understanding and Reasoning by supporting naming, memory, and flexibility may help to optimize capacity in this patient group.

KEY WORDS: dementia; consent; capacity; competency.

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With an aging U.S. population, physicians can anticipate providing care to increasing numbers of older adults with dementia or other mental disorders whose capacity to consent to specific medical treatments is diminished. Although a diagnosis of dementia in and of itself does not imply incapacity, groups of individuals with dementia have reduced consent capacity compared with healthy control groups.^{1–4}

Evaluating decisional capacity can be challenging, especially among older adults with mild-to-moderate dementia. Even *within-study samples*, rates of decisional incapacity in

demented patients vary widely depending on the clinician (from 0% to 90%)⁵ and the legal standard (from 0% to 67%) used.³ Interrater agreement for capacity is no better than chance (56%),⁵ possibly because physicians focus on different cognitive tasks to assess capacity.⁶

Rates of agreement may be improved when physicians are trained to evaluate specific legal standards.⁷ A widely accepted^{8,9} taxonomy of the legal standards or decisional abilities necessary for capacity to consent to medical treatment is: Understanding, Appreciation, Reasoning, and Expression of Choice (Table 1).

These findings raise several questions for the practicing clinician. If a physician knows a patient has dementia, how likely is it that decisional capacity is impaired? Which specific aspects of decision making are most difficult for patients with dementia? Which cognitive impairments associated with dementia (e.g., attention, memory, and planning) best predict decisional incapacity? How is decisional capacity likely to change over time?

This study aims to address these questions by examining: (1) the proportion of older adults with dementia who have impaired capacity for specific legal standards when considering a hypothetical treatment condition; (2) the frequency and extent of decisional capacity decrements within a 9-month time frame with respect to these legal standards; and (3) the cognitive impairments associated with dementia that predict progression of decisional incapacity. Based on these findings, the authors suggest strategies physicians can use to maximize decisional capacity in patients.

METHODS

Selection of Participants

Subjects were recruited as part of a larger study of consent capacity.³ Of 290 potential subjects referred for screening, 88 met screening criteria for the dementia group detailed below. The analysis presented in this paper is based on a subsample of 53 adults with dementia with complete data at baseline and 9-month follow-up, and a similarly aged comparison group of 53 healthy adults.

Participants with dementia were caregiver-, clinician-, or self-referred in response to announcements in veterans affairs (VA) hospital waiting rooms, senior programs (senior centers, senior housing, and councils on aging), or newspapers; some additional participants were recruited by a friend already in the study or other sources. Of those in the final dementia sample, 26 were referred through the VA, 15 through senior

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Table 1. Legal Standards for Capacity to Consent to Treatment

Understanding	The ability to comprehend diagnostic and treatment information
Appreciation	The ability to relate the treatment information to one's own situation, in particular, to believe the nature of the diagnosis and the possibility that treatment would be beneficial
Reasoning	The ability to rationally evaluate treatment alternatives by comparing risks and benefits in light of potential consequences and their likely impact on everyday life
Expressing a choice	The ability to communicate a decision about treatment

programs, 4 through newspaper advertisements, and 8 through friends or other sources. Cognitive status (orientation, 10-word memory, naming, nonverbal praxis, attention, and calculation) was screened with the modified version of the telephone interview for cognitive status (TICS-M).¹⁰ Potential subjects with psychiatric conditions that could affect capacity were screened out with the Geriatric Depression Scale (GDS)¹¹; (excluded if 10 or more positive items) and Brief Symptom Inventory (BSI)¹²; (excluded if T scores exceeded 70).

Dementia group participants submitted medical records and completed the dementia diagnostic screening questionnaire (DDSQ)¹³ to provide information on symptoms of and risk factors for dementia. Clinical diagnoses of dementia were made by consensus of a geropsychiatrist (R.J.G.) and geropsychologist (J.M.) using DSM-IV¹⁴ criteria. Of the 53 subjects with dementia used in this analysis, 28 (52.8%) had mild dementia, and 25 (47.2%) had moderate dementia, based on a suggested TICS-M cutoff score of 30/31.¹⁵ Nineteen (36%) of participants in the dementia subsample were assessed to have possible or probable Alzheimer's disease (AD); 14 (26%) had risk factors for vascular dementia (VD) (either alone or in the presence of AD); and 20 (38%) had risk factors for multiple etiologies of dementia (e.g., traumatic brain injury, history of alcohol dependence), either alone or in addition to AD/VD.

Participants in the comparison group were from the same sources as the dementia group. Of those in the final sample, 19 were recruited through the VA, 17 through senior programs, 10 through newspapers, and 7 through friends or other sources. More participants in the patient sample were recruited through VA clinical sources, whereas more participants in the healthy comparison group were recruited through senior programs and newspapers. However, these differences were not statistically different.

Participants in the comparison group completed a 37-item Health Screening Questionnaire¹⁶ to eliminate those with risk factors for dementia (e.g., "have you ever had a stroke or TIA?"; "do you have Parkinson's disease?"). Healthy participants were excluded if depression¹¹ or psychiatric¹² screening scores were elevated, or if cognitive screening scores¹⁰ impaired. All study participants were community dwelling.

Description of Participants

Demographic characteristics are presented in Table 2. All participants were English speaking. In contrast to the preponderance of women in the older population in general, this sample

had more men because VA facilities were principal recruitment sites.

Informed Consent for Research

All participants provided informed consent as approved by VA and Medical School Human Subjects committees. Subjects were compensated for their time.

Testing

Subjects participated in face-to-face decision-making capacity and neuropsychology evaluation at the medical center, at a convenient location near the subject's home (e.g., senior center) or in the participant's home, depending upon subject preference. Re-testing occurred 9 months $\pm$ 2 weeks after the initial testing. A 9-month re-test period was selected prospectively to allow for a clinically relevant interval and to conform to a grant funding cycle.

Capacity Assessment. Decision-making capacity was assessed with the MacArthur Competence Assessment Tool-Treatment (MacCAT-T).¹⁷ The MacCAT-T utilizes a structured interview to assess the 4 legal standards for treatment consent capacity (Table 3). In this study, a hypothetical scenario involving a choice between amputation or vascular surgery for a nonhealing toe ulcer was utilized.³

Diagnostic and treatment information was disclosed in a stepwise manner, focusing first on the disorder, then on one treatment, next on the second treatment. Each piece of diagnostic and treatment information was presented in a simplified manner, using cues when necessary, to maximize comprehension and minimize memory demands.

Neuropsychological Assessment. Areas of cognitive function commonly used in dementia evaluation and representing do-

Table 2. Demographic Characteristics of Dementia and Healthy Comparison Groups

Variable	Dementia Group (N=53)	Comparison Group (N=53)	Significance (t or χ^2)
Age (y)			
Mean	75.81	73.09	P=.03
SD	6.22	6.53	
Education (y)			
Mean	13.87	14.09	P=.69
SD	3.01	2.76	
Gender			
Female (%)	39.6	47.2	P=.43
Male (%)	60.4	52.8	
Race			
African American (%)	3.8	5.7	P=.65
Caucasian (%)	96.2	94.3	
Marital status			
Married (%)	60.4	55.8	P=.56
Single* (%)	39.6	44.2	
Income (%)			
\$0 to 15,000	41.5	35.9	P=.43
\$15,001 to 30,000	32.1	28.3	
\$30,001 to 45,000	13.2	18.9	
\$45,001 to 60,000	1.9	5.7	
Over \$60,001	0	3.8	
Not reported	11.3	7.4	

*Divorced, widowed, or never married.

mains associated with impaired capacity^{18,19} were assessed using a neuropsychological battery: Wechsler Memory Scale, 3rd edn, Digit Span Forward and Backward, and Logical Memory Immediate and Delayed Subtests; Trails A and B; Wechsler Adult Intelligence Scale, 3rd edn Vocabulary subtest; Boston Naming Test; Cognitive Battery for Dementia Mazes Test; Visual Search and Attention Test; and Controlled Oral Word Association Test. All tests are described in Lezak¹⁸ and were administered and scored according to standardized instructions.

Statistical Analyses

Data were analyzed with SPSS version 10.0. To determine the percentage of participants scoring in an impaired range for each legal standard, participants were rated as impaired if their score for that standard fell 2.5 SD below the comparison group mean, a stringent impairment cutoff used in neuropsychological testing and in previous capacity research.^{3,18} Rates of impairment in the dementia and comparison groups were compared with χ^2 coefficients. To determine the percentage of participants with impaired overall capacity, participants were rated as impaired if their score for any legal standard was less than 2.5 SD below the comparison group mean, as impairment on any legal standard requires a clinical finding of incapacity; these groups were also compared with χ^2 coefficients.

To determine if decisional capacity changed over time, mean initial and 9-month capacity scores in dementia and comparison groups were compared using repeated measures ANOVA from the General Linear Model function of SPSS. Group was the between-subjects factor, and time (baseline vs 9 months) was the within-subjects factor. All demographic variables (age, sex, race, religion, marital status, and income) were included as covariates in the model, although only age differed significantly between groups (Table 2). This is an effective technique for addressing between-subjects differences in repeated measures models.

Stepwise discriminant function analysis²⁰ was used to determine the variables that best discriminated between those groups with and without overall capacity (at baseline and 9-month follow-up). For this procedure, subjects were classified as decisionally impaired or unimpaired based on overall capacity cutoffs as previously described. Neuropsychological test scores and demographic variables were selected as predictors according to the size of the correlation between baseline test performance and the discriminant function. Variables were

selected to enter the equation if the significance level associated with its *F* value was less than .05, and excluded if the significance level was greater than .10. Because of concerns for multicollinearity, scores for Immediate Logical Memory were eliminated from the analyses because Immediate and Delayed Logical Memory were highly correlated, and Immediate Logical Memory had the larger univariate correlation with other neuropsychological variables. Subgroup analyses based on presumptive dementia etiology were precluded by sample size.

RESULTS

Decisional Impairments

Initial Assessment. Four (7.5%) adults with dementia and no comparison subjects scored in the impaired range for Understanding ($\chi^2=4.16$, $P=.04$) (Table 4). One (1.9%) adult with dementia was impaired for Appreciation, 3 (5.7%) for Reasoning, and none for Expressing a Choice. Performance on these standards was not significantly different from comparison subjects. Combining across legal standards for overall capacity, 5 (9.4%) of those with dementia fell into the impaired range. Of note, 2 (3.8%) healthy subjects also fell into the impaired range for overall capacity, suggesting problems with measurement, transient impairment, or underrecognized cognitive dysfunction in these participants at the initial time period. Importantly, most adults, with or without dementia, were not impaired.

Nine-Month Follow-Up. Nine months later, 5 (9.4%) adults with dementia and no comparison subjects were impaired for Understanding ($\chi^2=5.24$, $P=.02$), and 12 (22.6%) dementia group subjects but no comparison subjects were impaired on Reasoning ($\chi^2=13.53$, $P<.001$) (Table 4). No adults with dementia were impaired on Appreciation, and one was impaired on Expressing a Choice. At 9 months, 14 (26.4%) adults with dementia were impaired for overall capacity, including the 5 who were initially impaired and an additional 9 who became impaired (compared with 0 in comparison group; $\chi^2=16.13$, $P<.001$).

Between initial and follow-up testing, mean Reasoning scores fell in the dementia group (initial $M=6.81$, $SD=1.26$; 9 months $M=5.92$, $SD=1.82$) but not in the comparison group (initial $M=7.28$, $SD=0.95$; 9 months $M=7.25$, $SD=0.87$), with a significant group $\times$ time interaction on re-

Table 3. Capacity Assessment on the MacCAT-T Using a Hypothetical Treatment Scenario

Legal Standard or Decisional Ability	No. of Items	Potential Range*	Description
Understanding	12	0 to 24	Examinees are asked to paraphrase "in your own words" diagnostic and treatment information. Key information is disclosed and, if missed, is cued with a question and, if still missed, is disclosed again.
Appreciation	2	0 to 4	After being provided information about treatment, examinees are asked (i) if there is "any reason to doubt" information about the condition; (ii) whether treatment "might be of benefit." Responses are scored to detect answers that reveal patently false beliefs.
Reasoning	4	0 to 8	After a treatment choice is made, examinees are asked questions that aim to discover reasoning based upon (i) comparison of treatments; (ii) consequences of treatments; (iii) everyday consequences of treatment alternatives. At the end of the interview, examinees' reasoning is rated for logical consistency.
Expressing a Choice	1	0 to 2	Near the end of the interview, examinees are asked to re state their choice. Examinees are permitted to change their mind, as long as they indicate a clear choice by the end of the interview.

*Scoring reflects items used in the hypothetical treatment scenario developed for this research project. For information on administering and scoring the standard clinical version, refer to Grisso and Appelbaum¹⁷

Table 4. Participants Scoring in the Impaired Range on the MacCAT-T Capacity Instrument Initially and at 9 Months

Legal Standard	Initial				9 Months			
	Dementia (N=53) (%)	Control (N=53) (%)	χ^2	P	Dementia (N=53) (%)	Control (N=53) (%)	χ^2	P
Understanding	7.5	0	4.16	.04	9.4	0	5.24	.02
Appreciation	1.9	1.9	0.00	1.00	0	0	—	—
Reasoning	5.7	1.9	1.04	.31	22.6	0	13.53	<.001
Expressing a Choice	0	0	—	—	1.9	0	1.01	.32
Any	9.4	3.8	1.38	.24	26.4	0	16.13	<.001

Participants were rated as impaired if scores fell 2.5 standard deviations below the control group mean.
MacCAT-T, MacArthur competence assessment tool-treatment.

peated measure ANOVA ($F=9.44$, $P=.003$). Mean Understanding scores remained stable within the dementia group (initial $M=17.17$, $SD=4.08$; 9 months $M=17.15$, $SD=4.60$), but there was a nonsignificant increase within the comparison group (initial $M=18.91$, $SD=3.02$; 9 months $M=19.49$, $SD=2.61$; $F=1.76$, $P=.19$). There were no other statistically significant group $\times$ time interactions. Posthoc t -tests showed that mean scores in the dementia group were impaired relative to comparison subjects at initial and 9-month assessments for Understanding (initial $t=2.49$, $P=.01$; 9-month $t=3.22$, $P<.01$) and Reasoning (initial $t=2.18$, $P=.03$; 9-month $t=4.77$, $P<.01$). Group effects were significant for Understanding ($F=7.10$, $P=.009$) and Reasoning ($F=18.08$, $P<.001$), but not for Appreciation ($F=0.22$, $P=.64$) or Expressing a Choice ($F=0.30$; $P=.59$). There was no significant main time effect.

Cognitive Predictors of Decisional Impairment. Baseline delayed Logical Memory successfully classified participants into impaired and unimpaired overall capacity groups at the initial time period by stepwise discriminant function analysis. Baseline Boston Naming, delayed Logical Memory, and Trails B together successfully classified participants into impaired and unimpaired capacity groups at the 9-month time period by stepwise discriminant function analysis. Performance on these cognitive tasks correctly classified 94.3% of participants as decisionally impaired or within normal limits at both the initial and 9-month time periods. Demographic variables were not predictive of group membership.

DISCUSSION

Older adults with dementia are at risk for diminished decision-making capacity. Physicians who treat older adults need to

know which health care decision-making tasks are most challenging for such patients in order to maximize decisional capacity when possible.

In this study, we found that almost one-tenth of adults with dementia were decisionally impaired when seen initially, and approximately one-fourth were impaired 9 months later. These rates of impairment are lower than seen in other studies, including outpatients with dementia² and long-term care patients.²¹⁻²³ The lower rate of incapacity found in this study may be attributable to the method of capacity assessment, which minimized memory demands and aimed to maximize capacity performance. Other studies have used unbroken presentation of longer treatment vignettes that may increase memory demands for patients with impaired memory.

In this study, participants with dementia could express a treatment choice, but that choice was not always supported by adequate Understanding and Reasoning. Those with decisional incapacity had problems with Understanding diagnostic and treatment information or Reasoning through risks and benefits, rather than in Appreciation (believing diagnostic and treatment information). These findings indicate that a clearly communicated treatment choice does not in itself convey capacity. Further, Appreciation, or trust of diagnostic and treatment information, may be less commonly impaired in individuals with dementia than it is in psychiatric patients.²⁴ In fact, older nonpsychiatric patients are more likely to acquiesce to doctors than to distrust them.²⁵

Initial decisional impairments were attributable to problems in Understanding and Reasoning, but subsequent declines were tied to decrements in Reasoning. Reasoning requires holding in mind 2 treatment alternatives, together with information about their associated risks and benefits, and comparing these alternatives in light of their likely impact on

Table 5. Clinical Strategies for Maximizing Decisional Capacity

Minimize background noise; speak slowly and directly; make eye contact with the patient
Break diagnostic and treatment information into small segments
Discuss 1 segment of information at a time
Inquire about understanding of such information with simple questions
Use cues, such as bulleted lists with key information, pictures, and diagrams
Allow extra time for responses and, in general, slow down the discussion process
Repeat and rephrase information that may not be understood
Summarize key aspects of information, such as reviewing key risks and benefits of each treatment, prior to asking the patient for treatment preference
Provide corrective feedback if the patient has misunderstood key information
Inquire directly about values or concerns that may underlie treatment preferences including concerns about pain, consideration of "being a burden," worries about finances, fears of dying, religious and cultural traditions
Focus on the most salient information for the patient in light of personal preferences and values, to minimize the amount of information the patient must balance when weighing preferences

one's own life. This complex mental processing is likely to become more difficult as dementia progresses. The simplified approach to disclosure and follow-up used in the MacCAT-T may have bolstered performance on Understanding in patients with dementia, but it did not support the complex processing required for Reasoning.

In this study, baseline delayed Logical Memory alone best classified individuals with impairment at the initial time period, whereas baseline naming, delayed Logical Memory, and Trails B best classified individuals with impairment at 9 months. Previous studies have found that problems with naming, memory, and executive function impact decisional capacity.^{19,25,26} Thus, problems with remembering information after a short delay, assigning language to remembered elements, and shifting back and forth between remembered elements, may best predict declining capacity. Paying special attention to those patients with problems in naming, delayed memory, and flexibility may best identify which patients are likely to be decisionally impaired.

In summary, all patients with dementia in this study conveyed a clear treatment choice, and almost all indicated trust and belief of the doctor, but not all of these patients could in fact demonstrate adequate Understanding of and Reasoning about diagnostic and treatment information. Over 9 months, decision-making capacity declined in dementia patients, attributable especially to decreasing Reasoning. Therefore, despite overt expression of a treatment choice and agreeableness with the doctor, consent capacity needs to be directly evaluated, and re-evaluated, over time.

Strengths and Limitations of the Study

This study is one of a small number of empirical studies of consent capacity in dementia, and the only one to examine the longitudinal course of capacity. This study relied on an instrument-based rating of capacity rather than a clinician rating. While instrument-based ratings improve on issues of low reliability between clinicians, and the instrument used here has been validated against clinician ratings, it will be important to extend this research in larger samples with other assessment methods. Studies that include clinician-based assessment of capacity and in vivo observation of clinician-patient dialogue may extend the generalizability of findings to clinical practice.

Several limitations are noted. In this study the capacity instrument was re-administered at a 9-month interval. Although practice effects in older adults for similar story-based testing are small,¹⁸ where present they would have masked some decisional decline. Second, the participant group in this study was not racially diverse. It will be especially important to extend capacity studies to individuals of diverse racial and ethnic backgrounds, as these may influence approaches to medical decision making.^{27,28} Subjects in this study had dementia of varied etiologies, with a range of severity. Subtype may be a useful indicator of future progression when dementia subtype is known with reasonable certainty. For example, individuals with Alzheimer's dementia are more likely to deteriorate than those whose underlying disease process (e.g., vascular disease, alcohol dependence) is not inevitably progressive. Future studies should examine rates of decisional decline in etiologically distinct dementia types of varying severity. Finally, although the sample size is considerably larger than those used in previous studies of consent capacity in de-

mentia (mean 30.4 subjects, 13 published studies),²⁹ it is not large in a statistical sense.

Clinical Strategies for Maximizing Decisional Capacity

Decision-making capacity is situation specific, and must be assessed for each informed consent situation. Physicians may optimize the decisional capacity of patients with dementia by supporting the specific cognitive functions that appear to be related to diminished capacity. Specifically, communication strategies that provide supports for memory and executive functions may strengthen Understanding and Reasoning, and may maximize decision-making abilities in older adults with dementia. Strategies that simplify the presentation and discussion of information, and that minimize distraction and information-overload, may improve decision making in older patients.³⁰ Further, some older adults may seek less information and focus quickly on key information using well-learned "rules of thumb" or intuitive decisional styles gained through experience.^{31,32} The clinician can support the decision making of such patients by helping them to clarify goals and values, and then to focus in on key information in light of those goals and values.³³ Practical strategies for communicating with patients to support decision-making capacity are presented in Table 5. Further research is likely to increase the number and efficacy of such strategies.

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