

Capacity to Consent to Treatment: Empirical Comparison of Three Instruments in Older Adults With and Without Dementia

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Purpose: The purpose of this study was to compare adults with and without dementia on capacities to consent to treatment as assessed by three instruments. **Design and Methods:** Eighty-eight older adults with mild to moderate dementia were compared with 88 matched controls on four indices of legal competency to consent to medical treatment as assessed with three capacity instruments. **Results:** Mean performance of adults with dementia on a legal standard of understanding treatment information was impaired relative to controls on all instruments, and it was also impaired for an appreciation standard on one instrument and a reasoning standard on two instruments. However, in categorical ratings, most adults with dementia were within the normal range on all decisional capacities. Legal standards were operationalized differently across the three instruments for the capacities of appreciation and reasoning. **Implications:** Most adults with mild dementia can participate in medical decision making as defined by legal standards, although memory impairments may limit demonstration of understanding of diagnostic and treatment information. In dementia, assessments of reasoning about treatment options should focus on whether a person can describe salient reasons for a specific choice, whereas assessments of appreciation of the meaning of diagnostic

and treatment information should focus on whether a person can describe the implications of various choices for future states. More research is needed to establish the reliability and validity of assessment tools and of capacity constructs.

Key Words: Decision making, Competency, Memory, Risks and benefits

Questions about capacity to consent to treatment are typically raised when an individual with significant cognitive or psychiatric illness appears considerably impaired in her or his ability to understand and evaluate treatment information or to make or communicate treatment decisions. Historically, questions about consent capacity were restricted to adults with serious and persistent psychiatric illness (e.g., severe schizophrenia) or neurological illness (e.g., neurodevelopmental disorder). However, as the population ages, evaluations of decisional capacities are being made increasingly of individuals with late onset conditions affecting cognition, such as dementia (Zimny & Grossberg, 1998). Such evaluations can be particularly challenging as they are applied to individuals with a lifetime of experience and legally competent decision making. In addition, individuals with dementia may present with a range of impairment (from mild to moderate), depending on the disease stage, and a range of abilities (some preserved, some impaired), depending on the disease etiology (Riley, 1999).

Most evaluations of decisional capacity are made on the basis of a clinical interview, although these can be unreliable (Kaplan, Strange, & Ahmed, 1988; Markson, Kern, Annas, & Glantz, 1994; Marson, McInturff, Hawkins, Bartolucci, & Harell, 1997; Rutman & Silberfeld, 1992). Marson and colleagues (1997) found that physicians achieved only a 56% judgment agreement ($\kappa = .14$) in evaluating consent

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Table 1. Definitions of Decisional Capacities Important in Legally Competent Decision Making

| Capacity | Definition |
|---------------------|--|
| Understanding | The ability to comprehend diagnostic and treatment-related information and to demonstrate that comprehension; involves ability to attend, encode, store, and retrieve newly presented words and phrases |
| Appreciation | The ability to determine the significance of treatment information relative to one's own situation, focusing on beliefs about the actual presence of the diagnosis and the possibility that treatment would be beneficial; involves insight, judgment, and foresight |
| Reasoning | The process of comparing alternatives in light of consequences, through integrating, analyzing, and manipulating information; involves the ability to provide rational reasons for a treatment decision, to manipulate information rationally, to generate consequences of treatments for one's life, and to compare those consequences in light of one's values |
| Expressing a choice | The ability to communicate a decision about treatment, applying to individuals who cannot or will not express a choice, or who are ambivalent |

capacity in mildly demented patients on the basis of videotaped structured interviews. However, a second study found improvement in interrater reliability when physicians were trained to assess specific decisional capacities important for legal competency (Marson, Earnst, Jamil, Bartolucci, & Harrell, 2000): (a) understanding, (b) appreciation, (c) reasoning, and (d) expressing a choice, as explained in Table 1. These capacities, also known as legal standards for competency, were first identified by review of case law and statutes (Roth, Meisel, & Lidz, 1977) and refined further by legal scholars, clinicians, and ethicists (Berg, Appelbaum, & Grisso, 1996; Tepper & Elwork, 1984; see Grisso & Appelbaum, 1998, for more discussion).

Several researchers have attempted to improve the reliability and validity of clinical evaluations of these decisional capacities by developing related questions, interview guides, or structured tools (Edelstein, 2000; Grisso & Appelbaum, 1998; Janofsky, McCarthy, & Folstein, 1992; Marson, Ingram, Cody, & Harrell, 1995). Such endeavors hold the promise of translating legal terms into clinically useful language. However, some worry that these efforts could oversimplify the evaluation task, and thereby inadvertently decrease reliability, validity, and the protection of rights (Kapp & Mossman, 1996). Indeed, those who have developed such instruments have cautioned that instruments be used to contribute to, not substitute for, an individualized assessment and interpretation.

In summary, we know that clinical judgments about consent capacity can be challenging and at times unreliable, especially in older adults who have late onset neurological conditions with subtle cognitive changes. Fortunately, there is an emerging consensus about the decisional capacities that are relevant for legal competency. Further, a number of instruments have been proposed to assess these legal standards. In our view, an important next step is the empirical study of these instruments with the goal of extending knowledge about the construct of competency and its component domains.

Research Goals

We investigated questions concerning two issues. First, what medical decision-making-capacity impairments are observed in dementia? Second, how are capacity constructs defined in dementia?

Capacity Impairments in Dementia.—How do adults with early dementia compare with healthy control-group adults on decisional capacities relevant for legal competency to consent to treatment? What aspects will individuals with dementia find challenging? Which decision-making capacities are well preserved in early dementia?

Capacity Constructs in Dementia.—How have different investigators operationalized legal consent capacities? How well do the instruments distinguish patient groups, and what does this tell us about the utility of different operationalizations of decisional capacities in dementia?

Methods

Participants

Eighty-eight men and 88 women were recruited; sample size was determined on the basis of a priori power analyses. Forty-four of the men and 44 of the women were clinically assessed to have dementia of heterogeneous etiologies, as described in the paragraphs that follow. Mean age was 73.77 years ($SD = 6.56$) and mean years of education was 13.95 ($SD = 2.83$). Those in the dementia group were slightly older than those in the control group ($M = 75.32$, $SD = 6.23$ vs. $M = 72.23$, $SD = 6.55$), $t = -3.21$, $p < .01$). Education did not differ between the dementia group and the control group, although, over both groups, it was higher in men than in women ($M = 14.55$, $SD = 2.97$ vs. $M = 13.26$, $SD = 2.56$), $t = 2.85$, $p < .01$. Eleven (6.3%) participants identified their race as African American, 2 (1.1%) identified their

race as Native American, and 163 (92.6%) identified their race as Caucasian. Gross pretax income was \$0–15,000 for 40.3% of the participants, \$15–30,000 for 32.7%, \$31–45,000 for 19.5%, and more than \$46,000 for 7.6% of the sample. Ninety-four percent of the participants reported English as their first language; 100% spoke English now.

Procedures

Recruitment.—Older adults with and without dementia were identified through fliers circulated in hospital waiting rooms, senior centers, and senior housing, and through advertisements placed in community newspapers, council of aging newsletters, and an Alzheimer Association newsletter. Efforts were made to recruit participants of color through special solicitation.

Screening.—Interested adults telephoned the research coordinator, who completed a modified version of the Telephone Interview for Cognitive Status (TICS; Brandt, Spencer, & Folstein, 1988), assessing orientation, 10-word memory, naming, nonverbal praxis, attention, and calculation. Because of the importance of delayed recall in the diagnosis of dementia, the TICS was modified to include delayed recall of the 10-word list for a total possible score of 50.

To exclude individuals with psychiatric conditions that might interfere with cognition, all participants completed the Geriatric Depression Scale—short form (GDS; Sheikh & Yesavage, 1986), and the Brief Symptom Inventory (BSI; Derogatis, 1975). Those individuals scoring above a raw score of 10 on the GDS and a *T* score of 70 on the BSI were excluded. Thirteen individuals were excluded for elevated scores on the GDS or BSI.

All potential participants for the dementia group completed further screening to provide information necessary for a clinical diagnosis of dementia based on diagnostic criteria from the *Diagnostic and Statistical Manual of Mental Disorders* (4th ed.; *DSM-IV*; American Psychiatric Association, 1994). Of note, as this study did not focus on capacity impairments associated with specific forms of dementia, we included all individuals who met *DSM-IV* criteria for dementia attributable to any of the following subtypes: Alzheimer's, vascular, and Parkinson's disease, and alcohol-induced persisting. When possible, on the basis of existing information, we diagnosed the subtype. Most participants had dementia that was due to vascular etiology (27%), followed by multiple etiologies (27%).

Potential dementia participants completed the Dementia Diagnostic Screening Questionnaire (DDSQ; Rogers & Meyer, 1988), with the help of a caregiver if needed. The 94-item questionnaire asks about subjective memory difficulties, (e.g., “do you

have trouble remembering things?”) and risk factors for specific dementia subtype etiologies (e.g., for vascular dementia, “have you ever had heart surgery?”; for substance-induced persisting dementia, “have you ever stopped drinking because you felt you were drinking too much?”). Potential participants in the dementia group also provided medical records, including blood work, neurological examinations, and head computed tomographic or magnetic resonance images. Clinical diagnoses of dementia were made by consensus of a geropsychiatrist and geropsychologist using *DSM-IV* criteria on the basis of cognitive screening scores, reports of memory and behavioral problems, presence of risk factors for dementia, and medical records. Twenty-four individuals who presented with memory complaints but for whom a dementia diagnosis could not be made were excluded from the study.

All potential participants for the control group completed a 37-item Health Screening Questionnaire (Christensen, Moye, Armson, & Kern, 1992) to screen for serious health problems likely to cause memory impairment (e.g., “have you ever had a stroke or transient ischemic attack [TIA]?”). Thirty individuals who endorsed at least one of these health problems were excluded from the normal control group. In addition, four individuals who passed screening did not proceed to testing as a result of health or scheduling problems.

Informed Consent.—All participants completed informed consent as approved by hospital and medical school Internal Review Board and Human Subjects committees. As we aimed to recruit individuals in the early stages of dementia, we anticipated that individuals would retain the capacities to consent to low-risk procedures such as this study (not involving intervention, and with risks only of inconvenience, boredom, and fatigue), and have not been adjudicated for legal incompetency. However, because our study involved individuals selected because of cognitive impairments, special attention was given to the informed consent process. For informed consent to be complete, information about the study purpose, risks, and benefits was disclosed to all participants in simple direct language, in written and verbal formats. The examiner inquired as to whether the participant understood the study information, risks and benefits, and answered any questions. If the participant had a legal guardian (true for one subject in the study), the study information was disclosed conjointly to the participant and the guardian, and both signatures were obtained indicating the participant's assent and the guardian's consent. Participants were clearly informed that they could discontinue testing at any time if they disliked the testing or were fatigued. All but three participants finished the entire testing protocol.

Table 2. Comparison of Methods of Assessing Capacities for Each Instrument

| Capacity | Method |
|---------------------|---|
| Understanding | |
| MacCAT-T | Paraphrasing, “in your own words,” of diagnostic and treatment information |
| HCAI | Series of questions about information described in the condition and treatment |
| CCTI | Series of questions about the details of information described in two vignettes |
| Appreciation | |
| MacCAT-T | Asks (a) if there is “any reason to doubt” information about the condition and (b) whether treatment “might be of benefit” |
| HCAI | Asks why the doctor wants the person to take the treatment (in the first vignette only) |
| CCTI | Asks (a) preparation: what would need to be done to prepare for the chosen treatment; (b) projection: what life will be like 1 year after the treatment |
| Reasoning | |
| MacCAT-T | Asks for statements that indicate (a) comparison of treatments; (b) consequences of treatments; (c) everyday consequences of treatment alternatives; and (d) logical consistency of reasoning |
| HCAI | Asks why a choice was made, with query and credit for the risks and benefits considered |
| CCTI | Asks to give all the reasons why a choice was made, credit given for the total number and accuracy of reasons provided |
| Expressing a choice | |
| MacCAT-T | Rates if there is a clear choice |
| HCAI | Rates whether a choice is made |
| CCTI | Rates whether a choice is made for each vignette |

Notes: MacCAT-T = MacArthur Competence Assessment Tool for Treatment; HCAI = Hopemont Capacity Assessment Interview; CCTI = Capacity to Consent to Treatment Instrument.

Testing.—Participants who screened into the final dementia or control groups were invited to participate in face-to-face, decision-making-capacity evaluations using standardized protocols. The order of the capacity instrument administration was counter-balanced across the three instruments to avoid order effects. Testing occurred at the medical center, at a convenient location near the participant’s home (e.g., senior center) or in the participant’s home, depending on the individual’s preference. Testing lasted approximately 120 min; participants were given at least one break but were offered other breaks periodically throughout testing. Of note, all participants, both in the dementia and control groups, had primary attention abilities within normal limits (Digit Span combined score at least in the low average range; standard score > 6). Participants were compensated for their time.

Participants were evaluated with three instruments designed to assess medical decision-making capacity: (a) the MacArthur Competence Assessment Tool for Treatment (MacCAT-T; Grisso & Appelbaum, 1998); (b) the Hopemont Capacity Assessment Interview (HCAI; Edelstein, 2000); and (c) the Capacity to Consent to Treatment Instrument (CCTI; Marson et al., 1995). Each instrument presents a hypothetical diagnosis and treatment alternatives, and each asks the individual to demonstrate his or her capacity to understand and appreciate diagnostic and treatment information and to explain the reasoning behind choosing one treatment alternative over another. Each instrument has a method for evaluating and rating the four legal standards, as presented in Table 2. In this study, the MacCAT-T

used a vignette involving treatment of a nonhealing toe ulcer with surgery or amputation. The medical component of the HCAI has two vignettes about treatment of an eye infection and the administration of cardiopulmonary resuscitation to a friend; the use of the third person is intended to avoid personalization of information when used for research purposes (e.g., “but I don’t have that condition”). The CCTI consists of brain cancer and heart surgery vignettes.

Statistical Analyses

An analytic strategy was developed in reference to several considerations. Because the capacity instruments are relatively new, and there is limited information about the reliability and validity of the capacity scores, we performed a series of simple comparative analyses. We avoided using composite scores, as we did not want to compound potential problems with reliability and validity across capacity subscores or instruments. We modeled our analytic approach after Marson and colleagues (1995) to permit comparisons between our findings and theirs. Consistent with the notion of moving away from global competency to instead consider specific decisional capacities and their potentially unique construct definitions, we analyzed data for each decisional capacity separately.

Mean Comparisons.—We compared group differences on individual capacities as measured by each instrument in a series of analyses of covariance (ANCOVAs), controlling for age, gender, and

Table 3. Mean Group Differences on Decisional Capacities

| Capacity-Instrument | No. of Items | Potential Range | Control Group | | Dementia Group | | F | df |
|---------------------|--------------|-------------------|---------------|--------|----------------|---------|--------|--------------------|
| | | | M | (SD) | M | (SD) | | |
| Understanding | | | | | | | | |
| MacCAT-T | 12 | 0–24 | 18.84 | (3.03) | 16.92 | (4.17) | 7.13* | 4,162 ^b |
| HCAI | 14 | 0–28 | 25.49 | (1.86) | 24.19 | (3.38) | 5.34* | 4,171 |
| CCTI | 18 | 0–130 | 55.61 | (8.33) | 45.99 | (13.98) | 26.44* | 4,170 |
| Appreciation | | | | | | | | |
| MacCAT-T | 2 | 0–4 | 3.78 | (0.57) | 3.79 | (0.54) | 0.18 | 4,162 |
| HCAI | 1 | 0–2 | 1.77 | (0.47) | 1.66 | (0.52) | 1.93 | 4,173 |
| CCTI | 4 | 0–8 | 6.20 | (1.34) | 4.98 | (1.60) | 11.03* | 4,169 |
| Reasoning | | | | | | | | |
| MacCAT-T | 4 | 0–8 | 7.28 | (0.95) | 6.67 | (1.32) | 7.83* | 4,162 |
| HCAI | 3 | 0–6 | 4.95 | (1.33) | 5.07 | (1.29) | 0.66 | 4,171 |
| CCTI | 2 | 0–20 ^a | 5.02 | (2.00) | 3.91 | (1.92) | 11.84* | 4,174 |
| Expressing a choice | | | | | | | | |
| MacCAT-T | 1 | 0–2 | 1.97 | (0.23) | 1.96 | (0.19) | 0.06 | 4,162 |
| HCAI | 3 | 0–6 | 5.88 | (0.37) | 5.79 | (0.56) | 1.01 | 4,171 |
| CCTI | 2 | 0–4 | 3.98 | (0.21) | 3.94 | (0.32) | 0.70 | 4,170 |

Notes: MacCAT-T = MacArthur Competence Assessment Tool for Treatment; HCAI = Hopemont Capacity Assessment Interview; CCTI = Capacity to Consent to Treatment Instrument.

^aCCTI total scores for reasoning were standardized to 10 points per vignette to adjust for different potential total scores on reasoning associated with different treatment choices.

^bTwelve individuals completed an earlier version of the MacCAT-T. The total subsample receiving the final version was $n = 164$.

* $p < .01$, F for group effect controlling for age, education, and gender.

education. For the capacities with significant main effects for group, we evaluated subscores (where applicable: MacCAT-T appreciation and reasoning, CCTI appreciation) with independent t tests.

Frequency Comparisons.—We also evaluated group differences by comparing the number of individuals in the dementia and control groups falling within normal limits, in the mild to moderately impaired category, or the severely impaired category on the basis of cut scores derived from control performance, following Marson and colleagues (1995). Such categorical comparisons are important because they demonstrate the proportion of individuals with dementia who do and do not fall within impaired ranges on capacity testing. We considered persons with capacity scores $< 1.5 SD$ below the control-group mean as mild to moderately impaired, and those with scores $< 2.5 SD$ below the normal mean as severely impaired. We evaluated prediction of capacity-impairment ranking by dementia-severity level through Goodman-Kruskal gamma coefficients (for ordinal data). We determined dementia severity on the basis of the TICS-m cognitive screening score. We used a cutoff score of 30/31 as suggested by Welsh, Breitner, and Magruder-Habib (1993), which in this sample corresponded to 2.0 SD s below our control-group mean. We assessed forty-eight participants as having mild dementia; 40 as having moderate dementia. In addition, we determined the overall difficulty

level of the capacity measure as the proportion correct (percent falling within normal limits) for the total sample. This provided additional information about the measurement properties of the capacity instruments.

Results

Mean Comparisons

Mean group differences are presented in Table 3. Participants with dementia performed worse than controls for the decisional capacity of understanding on all three instruments. For the capacity of appreciation, participants with dementia were equivalent to healthy control-group participants except on the CCTI, where individuals with dementia performed worse. In follow-up t tests on subscores for CCTI appreciation, individuals with dementia performed worse than control-group individuals on appreciation as indicated by future preparation ($M = 2.81$, $SD = 1.21$ vs. $M = 3.58$, $SD = .89$); $t = 4.75$, $p < .01$, and future projection ($M = 2.16$, $SD = .88$ vs. $M = 2.62$, $SD = .90$) $t = 3.32$, $p < .01$.

For the capacity of reasoning, individuals with dementia performed worse than control-group individuals as measured by the MacCAT-T and CCTI, but not the HCAI. In follow-up t tests on subscores for MacCAT-T reasoning, individuals with dementia performed worse than those in the control group on comparative reasoning ($M = 1.51$, $SD = .73$

Table 4. Percentage Impaired for Each Capacity by Dementia Severity Level

| Capacity-Instrument | Group | Within Normal Limits (%) | Mild to Moderately Impaired (%) | Severely Impaired (%) | γ | Difficulty |
|---------------------|--------------------------------|--------------------------|---------------------------------|-----------------------|----------|------------|
| Understanding | | | | | | |
| MacCAT-T | Control ^a | 89.9 | 10.1 | 0.0 | | |
| | Mild dementia ^b | 85.4 | 12.2 | 2.1 | | |
| | Moderate dementia ^c | 48.7 | 32.4 | 18.9 | .58* | .78 |
| HCAI | Control | 93.2 | 5.7 | 1.1 | | |
| | Mild dementia | 89.4 | 8.5 | 2.1 | | |
| | Moderate dementia | 63.2 | 13.2 | 23.7 | .62* | .86 |
| CCTI | Control | 94.3 | 5.7 | 0.0 | | |
| | Mild dementia | 78.3 | 15.2 | 6.5 | | |
| | Moderate dementia | 33.3 | 30.8 | 35.9 | .82* | .76 |
| Appreciation | | | | | | |
| MacCAT-T | Control | 94.9 | 3.8 | 1.3 | | |
| | Mild dementia | 97.9 | 2.1 | 0.0 | | |
| | Moderate dementia | 94.6 | 2.7 | 2.7 | .06 | .96 |
| HCAI | Control | 79.5 | 18.5 | 2.3 | | |
| | Mild dementia | 83.3 | 16.7 | 0.0 | | |
| | Moderate dementia | 48.7 | 46.2 | 5.1 | .38* | .74 |
| CCTI | Control | 89.5 | 9.3 | 1.2 | | |
| | Mild dementia | 76.1 | 19.6 | 4.3 | | |
| | Moderate dementia | 51.3 | 43.6 | 5.1 | .59* | .77 |
| Reasoning | | | | | | |
| MacCAT-T | Control | 96.2 | 2.5 | 1.3 | | |
| | Mild dementia | 83.3 | 10.4 | 6.3 | | |
| | Moderate dementia | 75.7 | 13.5 | 10.8 | .58* | .88 |
| HCAI | Control | 90.9 | 6.8 | 2.3 | | |
| | Mild dementia | 100.0 | 0.0 | 0.0 | | |
| | Moderate dementia | 86.8 | 7.9 | 5.3 | .00 | .93 |
| CCTI | Control | 93.2 | 5.7 | 1.1 | | |
| | Mild dementia | 87.5 | 10.4 | 2.1 | | |
| | Moderate dementia | 70.0 | 27.5 | 2.5 | .50* | .79 |
| Expressing a choice | | | | | | |
| MACCAT-T | Control | 98.7 | 0.0 | 1.3 | | |
| | Mild dementia | 97.9 | 2.1 | 0.0 | | |
| | Moderate dementia | 94.6 | 5.4 | 0.0 | .46 | .97 |
| HCAI | Control | 88.6 | 10.2 | 1.1 | | |
| | Mild dementia | 89.4 | 6.4 | 4.2 | | |
| | Moderate dementia | 81.6 | 7.9 | 10.5 | .18 | .87 |
| CCTI | Control | 98.9 | 0.0 | 1.1 | | |
| | Mild dementia | 95.8 | 2.1 | 2.1 | | |
| | Moderate dementia | 97.5 | 0.0 | 2.5 | .31 | .98 |

Notes: MacCAT-T = MacArthur Competence Assessment Tool for Treatment; HCAI = Hopemont Capacity Assessment Interview; CCTI = Capacity to Consent to Treatment Instrument. Mild to moderately impaired = ≤ 1.5 SD below normal mean; severely impaired = ≤ 2.5 SD below normal mean. The difficulty level is the proportion correct for the total sample.

^a $n = 88$; ^b $n = 48$; ^c $n = 40$.

* $p < .01$, Goodman-Kruskall gamma.

vs. $M = 1.82$, $SD = .50$), $t = 3.21$, $p < .01$, but they were equivalent on other MacCAT-T subscores for reasoning. There were no differences between participant groups on the capacity of expressing a choice as measured by all three instruments.

Frequency Comparisons

The percentage of individuals falling within normal limits, the mild to moderately impaired category, or the severely impaired category within

participant groups is presented in Table 4. Of note, for almost all capacities, the majority ($>50\%$) of individuals with dementia performed within normal limits.

For the capacity of understanding, the majority (89.9–94.3% across tests) of control-group individuals performed within normal limits, whereas adults with mild dementia performed slightly less well (78.3–89.4% across tests within normal limits), and adults with moderate dementia had considerable difficulties (only 33.3–48.7% within normal limits). On all instruments, group membership was

significantly associated with impairment rankings, as indicated by gamma coefficients. Difficulty level (p) ranged from .76 on the CCTI to .86 on the HCAI.

For the capacity of appreciation on the MacCAT-T, almost all the individuals in both groups performed within normal limits, and the overall proportion correct was very high ($p = .96$); group membership was not associated with impairment rankings. On the HCAI, many control-group individuals were rated as impaired (20.8% falling into mild to moderately or severely impaired categories), which was greater than individuals with mild dementia. However, most individuals with moderate dementia (51.3%) fell into the impairment range. Group membership was significantly associated with impairment ranking, although the gamma coefficient was only moderate in size. On the CCTI, the majority of controls performed within normal limits, whereas adults with mild dementia did less well (78.1% within normal limits), and those with moderate dementia did least well (51.3% within normal limits). Group membership was significantly associated with impairment rankings.

On the capacity of reasoning as measured by the MacCAT-T and CCTI, almost all control-group individuals scored within normal limits, whereas adults with mild dementia did less well (12.5–16.7% in the impaired ranges), and adults with moderate dementia did the worst (24.3–30.0% in the impaired ranges). Group membership was significantly associated with capacity impairments. Alternatively, on the HCAI, more control-group persons fell in the impaired categories (9.1%) than did those with mild dementia (0%). Group membership was not associated with capacity impairments, and the overall proportion correct was high ($p = .93$).

On the capacity of expressing a choice, almost all adults in all groups fell in the normal range on the MacCAT-T and CCTI, and the overall proportion correct was high. However, on the HCAI, 11.3% of the control-group individuals fell in the impaired categories whereas 10.6% of those with mild dementia and 18.4% of those with moderate dementia also did.

Discussion

This study compares differences between adults with and without dementia on four decisional capacities associated with legal standards for competency to consent to treatment. An advantage to the present study is that it compares group performance on these capacities across three instruments, with a larger sample size than in earlier reports with these instruments. Thus, this study investigates the capacity impairments associated with dementia as well as the utility of various instruments in such capacity assessment.

Prior to discussing the results, we note several limitations to this study. First, we recruited individuals with dementia of heterogeneous causes. Although we feel this increases the generalizability of our findings to the types of patients seen in our clinical practice, who most often present with multiple risk factors for different forms of dementia, it means we cannot comment on patterns of deficits associated with specific forms of dementia (e.g., Alzheimer's disease). Second, the decision-making-capacity measures used in this study were recently developed, and information on reliability, validity, and normative properties is limited. Finally, demographic variables suggest our sample is not equivalent to the U.S. population. Although we made special efforts to recruit individuals of color, 93% of our participants were Caucasian. In addition, 40% of our sample had a high school education (lower than the current national mean). Furthermore, although our income data are comparable with the national median, financial compensation may have attracted individuals with greater financial needs. Thirty-nine percent of our sample was recruited from VA clinics, which likely influenced these sample characteristics.

Understanding

The standard for legally competent understanding concerns whether the individual can comprehend diagnostic and treatment information. In each of the instruments utilized here, information about a diagnosis and treatment is disclosed in clear, direct language. Two instruments (the CCTI and the HCAI) assess the individual's capacity for understanding by asking the individual to recall specific aspects of the diagnostic and treatment information, whereas a third (MacCAT-T) asks the individual to paraphrase key information in his or her own words. In this study, adults with dementia performed worse than control-group adults on all these measures, consistent with previous research with the CCTI (Marson et al., 1995), suggesting some adults with dementia will have problems with the capacity of understanding, especially as dementia is more severe. However, it is important to note that most adults with mild dementia performed in the unimpaired range.

Despite these findings, several questions remain. How much and in what manner should information be disclosed? An individual's measured comprehension of disorder-and-treatment information would seem dependent on the amount and type of information initially disclosed about the disorder and treatments (Zwahr, 1999), a tricky business of determining just the right amount to disclose. Too much or too detailed information could overwhelm the patient and decrease comprehension, whereas disclosure of too little might withhold needed

information (Beisecker & Beisecker, 1990). Furthermore, one of the challenges of studying the capacity of understanding in the research setting is that hypothesized vignettes, in addition to requiring conjecture, are divorced from the issue of emotional impact. That is, in real clinical situations, emotional reactions to medical information, such as information about prognoses (e.g., life expectancy) and the impact of serious consequences of treatments (e.g., disability or pain) are likely to affect cognitive processing of that information (Pierce, 1996).

How precisely must information be recalled to exceed a legally competent threshold for understanding? For example, if the risk for death with surgery is 15%, must someone remember that specific number? To require high precision turns the assessment of understanding into an overly specific evaluation of verbal memory; to be too lax may wrongly minimize the failure to understand specific but critical information about treatments and consequences. Furthermore, it is unclear how much the ability to recall precise information affects the quality of the decision making. Older adults may use different decisional processes than younger adults (i.e., more automatic and less rule-based, relying more on doctor's advice and seeking out less information; Yates and Patalano, 1999), but arrive at similar decisions (Meyer, Russo, & Talbot, 1995). Thus, if an older adult with early dementia is unable to precisely restate disclosed medical information, we don't yet know that this necessarily means the decisional outcome (decision made) is in some way less valid.

What are the benefits and limitations of memory aids? Adults with clinically diagnosed memory impairments will obviously be at a disadvantage in evaluations of understanding that are structured to rely heavily on memory. However, because clinical situations are not structured as memory evaluations and often involve the use of notes, diagrams, references, and social support, future studies might also investigate the advantages and limits of such memory aids in medical decision making.

Appreciation

Appreciation is a more complex legal standard that is relevant for individuals who may have the capacity for understanding and technically competent reasoning, but fail to acknowledge that they truly have the condition or that the proposed treatments may be of benefit. It is especially applicable in individuals with delusional disorders, or individuals who are unreasonably suspicious or illogical. In this study, the concept of appreciation was operationalized quite differently on the various instruments as responses to the following: (a) direct questions about reasons to doubt conditions or treatments (MacCAT-T); (b) general questions about why the doctor is proposing a treatment

(HCAI); and (c) specific questions about future planning and outcomes (CCTI). As operationalized in these instruments, the concept of appreciation was not obviously impaired in older adults with dementia on the MacCAT-T or the HCAI but was on the CCTI. Of note, almost all participants scored within normal limits on MacCAT-T appreciation, rendering it not very relevant or useful for this population. On HCAI appreciation, a considerable portion of older control-group adults fell into the impaired range on the HCAI, suggesting the operationalization may be problematic.

In clinical situations, the capacity of appreciation may have different applications in different patient groups. For patients with psychiatric or personality disorders, failures to appreciate may be related to delusional symptoms. On the other hand, older adults without psychiatric disorders may in fact be more likely to acquiesce to treatment recommendations than to be unduly suspicious (Moye & Karel, 1999; Yates & Patalano, 1999). In our study, MacCAT-T and HCAI questions about reasons to doubt the doctor or why the doctor is recommending treatment were often met with puzzlement (i.e., "but why would I doubt what the doctor tells me?"), as might be indicated by the high proportion correct on the MacCAT-T and the misclassifications on the HCAI.

Appreciation as measured by foresight, such as on the CCTI, may be more applicable to older adults with capacity impairments unrelated to psychiatric conditions. In this study, adults with dementia had more difficulty with CCTI appreciation as measured by future planning and projection than did normal control-group adults. We would note, however, that such future planning and projection may be more or less relevant, depending on treatment choices. For example, in this study, the second vignette on the CCTI concerned a choice between a risky heart bypass and relatively safe medication. Participants had more difficulty stating what they would need to plan to do to take the medication. In some cases, difficulty in future planning and projection may be more of an indication of few perceived consequences (to plan for or to benefit from) rather than a failure to appreciate these.

In future studies it may be useful to continue to compare different approaches of assessing appreciation in different populations. Because this factor is difficult to assess in the research context, relying especially on discernment and relational aspects of medical decision making, it may be most helpful to track, record, and evaluate methods of assessing appreciation in real clinical situations.

Reasoning

Reasoning is a legal standard concerning whether individuals can compare risks and benefits in light of

treatment alternatives, and the impact of those risks and benefits for their own lives. Evaluation of reasoning may require the individual to be able to articulate and explain what may be a largely internal and intuitive process. The three instruments used in this study operationalized this standard differently. On the CCTI, individuals are asked for a list of the factual reasons supporting their decision to demonstrate reasoning. This list essentially repeats the items required in the assessment of understanding. As with CCTI understanding, individuals with dementia performed more poorly on reasoning when it was measured in this manner.

Findings for HCAI reasoning are comparable with these. The HCAI measured reasoning by asking participants to state risks and benefits associated with a treatment decision. This approach appeared similar to earlier questions for HCAI understanding, in which participants had to state treatment risks and benefits. However, individuals with dementia did not perform more poorly on the HCAI measure of reasoning in mean comparisons. Frequency ratings across impairment categories revealed that control-group individuals had about as much trouble with this as did those with moderate dementia. Of note, we used the "strict" scoring criteria of Edelstein, Nygren, Northrup, Staats, and Pool (1993), in which more points are given if participants provide both risks and benefits associated with treatment choices. We observed that some older participants, in explaining their treatment choice, focused on the salient reason (perhaps the one most relevant to them) rather than recite all reasons (including ones that are irrelevant to them). So, for example, in providing reasons for choosing treatment for an eye infection, the potential risk (stomachache) might not be mentioned in contrast to the potential benefit (cure an eye infection), if the benefit far outweighs the risk for that participant.

In the MacCAT-T's assessment of reasoning, the concept is teased apart with a series of questions. The MacCAT-T approach of pressing individuals to articulate treatment consequences in light of everyday consequences seems useful. This is because, in evaluating medical decision-making capacity, the validity of the decisional outcome relies entirely on the meaning of decisional options for the individual. This sort of drawing out of the reasoning process in light of values (e.g., Karel, 2000) appears much more relevant than a restating of reasons. In this way, competent medical decision making may be best described as a personally valid decision process rather than a rational one.

We were intrigued, nonetheless, that even when pressed for consequences of potentially significant treatments on the MacCAT-T (amputation causing problems with balance or surgery involving a long recovery), many participants with and without dementia appeared to minimize these. It seemed that many individuals in our older sample, survivors of

the Great Depression and World War II (39% veterans themselves), were reluctant to complain about the impact of lost toes or long recoveries. It may be that, in evaluating consequences, our participants completed an implicit application of values. That is, when asked to explain a treatment decision, the participants did not cite all consequences but only the salient ones within their life-span perspective. As another potential example of this tendency, we noted the low mean on CCTI reasoning for control-group adults (5.02 out of potential 20 points). Here again, participants may have given all the personally salient reasons for their choice but not every possible reason. Therefore, we recommend that adults with dementia should not be automatically penalized as lacking capacity if they do not recite all the possible rational reasons for their decision.

Nevertheless, older adults with memory impairments are likely to be at a considerable disadvantage in the capacity of reasoning when the decision is complicated, as indicated by lower performance in this study on the reasoning standard for adults with dementia as assessed by CCTI and MacCAT-T. We expect this is because this capacity requires comprehension, encoding, and retrieval over time, in the face of interference (i.e., remembering information about a first treatment choice while a second treatment choice is explained).

Choice

In this study, there were no differences between the dementia and the control groups in the capacity of expressing a treatment choice. Except for individuals at the most advanced stages of dementia, the issue is likely to be one of arriving at a treatment choice that fully considers all information rather than the simple ability to state a choice. Of interest, however, is the number of control-group individuals in the impaired range on HCAI choice. On the HCAI, participants are asked to make a choice for the (other) person described in the vignette. We found that some participants insisted, even when pressed, that they could not make a choice on behalf of another.

Conclusions

Dementia can pose difficulties for the recall of diagnostic and treatment information and for reasoning, particularly for the simultaneous comparison of alternatives in light of consequences. However, on the basis of this study, most individuals with mild dementia can participate in decision making as defined by legal standards for competency, and they should be encouraged to do so, perhaps with strategies to compensate for problems with verbal recall, complex simultaneous processing,

and intentional planning. Clinical evaluations of consent capacity should focus on the evaluation of legal standards for competency and be interpreted in light of case particulars, including values and life-span perspectives. In evaluating reasoning, it may be most helpful to take a person through the reasoning process, first by learning about the social and situational context for the health-care decision and then by asking about the consequences of treatment alternatives for those contexts. When information about the condition or treatment is excluded, it may be useful to check if that was because it was not remembered by the patient or because it was not important to the individual. In assessing appreciation, issues of trust may be less relevant for older adults without psychiatric conditions, whereas asking about future planning and projection may be more informative.

References

- American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington, DC: Author.
- Beisecker, A. E., & Beisecker, T. D. (1990). Patient information-seeking behaviors when communicating with doctors. *Medical Care*, *28*, 19–28.
- Berg, J. W., Appelbaum, P. S., & Grisso, T. (1996). Constructing competence: Formulating standards of legal competence to make medical decisions. *Rutgers Law Review*, *48*, 345–396.
- Brandt, J., Spencer, M., & Folstein, M. (1988). The telephone interview for cognitive status. *Neuropsychiatry, Neuropsychology, and Behavioral Neurology*, *1*, 111–117.
- Christensen, K. J., Moye, M., Armsron, R. R., & Kern, T. M. (1992). Health screening and random recruitment for cognitive aging research. *Psychology and Aging*, *7*, 204–208.
- Derogatis, L. R. (1993). *Brief Symptoms Inventory*. Minneapolis, MN: National Computer Systems.
- Edelstein, B. (2000). Challenges in the assessment of decision-making capacity. *Journal of Aging Studies*, *14*, 423–437.
- Edelstein, B. M., Nygren, M., Northrop, L., Staats, N., & Pool, D., (1993, August). *Assessment of the capacity to make financial and medical decisions*. Paper presented at the annual meeting of the American Psychological Association, Toronto, Canada.
- Grisso, T., & Appelbaum, P. S. (1996). *MacArthur Competence Assessment Tool for Treatment (MacCAT-T)*. Sarasota, FL: Professional Resource Press.
- Grisso, T., & Appelbaum, P. S. (1998). *Assessing competence to consent to treatment*. New York: Oxford.
- Janofsky, J. S., McCarthy, R. J., & Folstein, M. F. (1992). The Hopkins Competency Assessment Test: A brief method for evaluating patients' capacity to give informed consent. *Hospital and Community Psychiatry*, *43*, 132–136.
- Kaplan, K. H., Strange, J. P., & Ahmed, I. (1988). Dementia, mental retardation, and competency to make decisions. *General Hospital Psychiatry*, *10*, 385–388.
- Kapp, M., & Mossman, D. (1996). Measuring decisional capacity: Cautions on the construction of a "capacimeter." *Psychology, Public Policy, and Law*, *2*, 73–95.
- Karel, M. J. (2000). The assessment of values in medical decision making. *Journal of Aging Studies*, *14*, 403–422.
- Markson, L. J., Kern, D. C., Annas, G. J., & Glantz, L. H. (1994). Physician assessment of patient competence. *Journal of the American Geriatrics Society*, *42*, 1074–1080.
- Marson, D. C., Earnst, K. S., Jamil, F., Bartolucci, A., & Harrell, L. E. (2000). Consistency of physicians' legal standard and personal judgments of competency in patients with Alzheimer's disease. *Journal of the American Geriatrics Society*, *48*, 911–918.
- Marson, D. C., Ingram, K. K., Cody, H. A., & Harrell, L. E. (1995). Assessing the competency of patients with Alzheimer's disease under different legal standards. *Archives of Neurology*, *52*, 949–954.
- Marson, D. C., McInturff, B., Hawkins, L., Bartolucci, A., & Harrell, L. E. (1997). Consistency of physician judgments of capacity to consent in mild Alzheimer's disease. *Journal of the American Geriatrics Society*, *45*, 453–457.
- Meyer, B. J. F., Russo, C., & Talbot, A. (1995). Discourse comprehension and problem solving: Decisions about the treatment of breast cancer by women across the life span. *Psychology and Aging*, *10*, 84–103.
- Moye, J., & Karel, M. J. (1999). Evaluating decisional capacities in older adults: Results of two clinical studies. *Advances in Medical Psychotherapy*, *10*, 71–84.
- Pierce, P. F. (1996). When the patient chooses: Describing unaided decisions in health care. *Human Factors*, *38*, 278–287.
- Riley, K. P. (1999). Assessment of dementia in the older adult. In P. Lichtenberg (Ed.), *Handbook of assessment in clinical gerontology* (pp. 134–166). New York: Wiley.
- Rogers, R. L., & Meyer, J. S. (1988). Computerized history and self-assessment questionnaire for diagnostic screening among patients with dementia. *Journal of the American Geriatrics Society*, *36*, 13–21.
- Roth, L. H., Meisel, C. A., & Lidz, C. A. (1977). Tests of competency to consent to treatment. *American Journal of Psychiatry*, *134*, 279–284.
- Rutman, D., & Silberfeld, M. (1992). A preliminary report on the discrepancy between clinical and test evaluations of competency. *Canadian Journal of Psychiatry*, *37*, 634–639.
- Sheikh, J. I., & Yesavage, J. A. (1986). Geriatric depression scale: Recent evidence and development of a shorter version. *Clinical Gerontologist*, *5*, 165–173.
- Tepper, A., & Elwork, A. (1984). Competency to consent to treatment as a psychological construct. *Law and Human Behavior*, *8*, 205–223.
- Welsh, K. A., Breitner, J. C. S., & Magruder-Habib, K. M. (1993). Detection of dementia in the elderly using the telephone interview for cognitive status. *Neuropsychiatry, Neuropsychology, and Behavioral Neurology*, *6*, 103–110.
- Yates, J. F., & Patalano, A. L. (1999). Decision making and aging. In D. C. Park, R. W. Morrell, & K. Shifren (Eds.), *Processing of medical information in aging patients: Cognition and human factors perspectives* (pp. 31–54). Mahwah, NJ: Erlbaum.
- Zimny, G. H., & Grossberg, G. T. (1998). Guardianship of the elderly. In G. H. Zimny & G. T. Grossberg (Eds.), *Guardianship of the elderly* (pp. 3–24). New York: Springer.
- Zwahr, M. D. (1999). Cognitive processes and medical decisions. In D. C. Park, R. W. Morrell, & K. Shifren (Eds.), *Processing of medical information in aging patients: Cognition and human factors perspectives* (pp. 55–68). Mahwah, NJ: Erlbaum.

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