Published in final edited form as:

Am J Geriatr Psychiatry. 2008 August ; 16(8): 693–696. doi:10.1097/JGP.0b013e31816c7b54.

Everyday Decision-making Ability in Older Persons with Cognitive Impairment

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Abstract

Objective—To demonstrate the reliability and validity of the Assessment of Capacity for Everyday Decision-making (ACED), an instrument to evaluate everyday decision-making (EDM).

Methods—We administered the ACED to thirty-nine persons with very mild to moderate cognitive impairment and 13 cognitively intact caregivers.

Results—Intra-class correlation coefficients showed good reliability for the measures of understanding, appreciation and reasoning, and Cronbach alpha coefficients were ≥ 0.84 for all three decision-making abilities. The ACED also had a moderate to strong correlation with the MacCAT-T, a validated measure of decision-making capacity for medical treatment decisions, and measures of overall cognition. Associations with measures of executive function were mixed, with moderate correlations observed only with ACED understanding and reasoning performance.

Conclusion—The ACED is a reliable and valid measure to assess decision-making capacity. It may serve as an important addition to current methods used to assess EDM.

Keywords

Capacity; Decision-making; Activities of Daily Living; Cognitive Impairment

INTRODUCTION

Older persons who refuse assistance to address problems in performing instrumental activities of daily living (IADLs), as in cases of self neglect, present clinicians with ethical and clinical challenges. In these situations, clinicians need to assess the person's capacity to make a decision. This assessment may have substantial clinical implications that may include partial or complete conservatorship or guardianship.

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Presentation: This work was presented in the Presidential Poster Session at the American Geriatrics Society Meeting in Seattle, WA, on May 4th, 2007.

Disclosure: The authors report no conflicts of interest.

Although persons who demonstrate sufficient capacity have the right to refuse their clinicians' recommendations, no specific instrument efficiently evaluates a person's capacity to make a decision with regard to solving his or her own actual functional problems, referred to as everyday decision-making capacity. (1) Existing instruments assess a person's problem solving ability or use hypothetical scenarios (1,2). None effectively addresses a common clinical issue: are patients who refuse interventions to help them manage their IADL disabilities capable of making this decision?

This study reports on a novel instrument to measure everyday decision making capacity, the Assessment of Capacity for Everyday Decision-making (ACED). We report on its reliability and validity in a cohort of older persons with very mild to moderate cognitive impairment.

METHODS

Participants

Eligible persons had to require assistance in at least two of three IADLs: administering medications, preparing meals, and/or managing finances. We required disability in these tasks due to their association with adverse outcomes among persons with dementia. (3) Other inclusion criteria were: Folstein Mini-mental State Exam (MMSE) (4) score >12; English speaking; a caregiver able to describe the person's functional activities; and >6th grade reading level. Persons with untreated depression, active psychosis, or delirium were excluded. Thirty-nine (93%) of the 42 eligible persons being treated for cognitive difficulties at the Adler Center Geriatric Assessment Clinic at the Yale-New Haven Hospital agreed to participate.

We enrolled persons into three MMSE-defined categories: very mild (25 to 30), mild (20 to 24), and moderate (12 to 19) impairment. Thirty-six of the 39 (92%) participants had a diagnosis of dementia (50% Alzheimer's disease, 3% vascular dementia, and 47% unspecified type), and 3 had mild cognitive impairment.

Thirteen caregivers completed ACED interviews to serve as a comparison group. Although the caregivers are younger, they are an ecologically valid comparison group, being surrogate decision-makers for patients who lack capacity. All caregivers invited to be in the study agreed to participate.

Human Subjects Protections—All participants provided informed consent or their assent (when a proxy was required). The Yale University Human Investigation Committee approved this research.

Measurements

Data collection occurred at the clinic or the participant's home. A research assistant administered the MacCAT-T and collected all other data, and, blinded to the initial ACED interviews, performed an additional ACED interview in a patient subset. The ACED interviewer (J.M.L.) was blinded to the participants' cognitive testing and MacCAT-T interview.

Everyday Decision-making Capacity—The Assessment of Capacity for Everyday Decision-making (ACED) instrument measures the capacity to make decisions about solving functional problems (1). The ACED uses a semi-structured interview format to assess four decision-making abilities: understanding, appreciation, reasoning, and expressing a choice. (5) A copy of the ACED instrument and scoring criteria are available upon request (jason.karlawish@uphs.upenn.edu).

The interviewer collects information from caregivers regarding functional deficits to allow the ACED instrument content to be tailored to each patient. For standardized content, participants receive a copy of information about the functional problem, the options to address it, and the risks/benefits of these options, to minimize the influence of short-term memory.

The order and headings for the ACED questions are: understanding the problem, appreciating the problem, understanding the options to solving the problem, understanding the benefits and harms of the options, appreciating the benefits and harms of the options, expressing a choice, comparative and consequential reasoning about that choice, and its logical consistency. The content of the ACED varies for each of the three IADL tasks.

The interviewer scores responses using a three point scale: 0=inadequate, 1=marginal, or 2=adequate. To measure a participant's performance on each ability, we summed the question scores. Higher scores indicate better performance: understanding (0–10), appreciation (0–8), reasoning (0–10), and expressing a choice (0–2).

ACED interviewers asked the caregivers how they would make decisions to solve the patient's functional problems, just as a surrogate decision-maker does when a patient lacks capacity. Each interview takes 15–20 minutes.

Medical Decision-making Capacity—We used a modified version of the MacArthur Competency Assessment Tool for Treatment (MacCAT-T) (5) to assess the capacity of participants to make a decision about taking a medicine that could slow the progression of memory loss. This has been validated in persons with very mild to moderate severity AD. (6)

Cognitive Function—We administered the MMSE and three measures of executive function (the Trails A & B and the Controlled Oral Word Fluency Test (COFL) (7)) because they have been previously identified as predictors of decision-making ability. (8)

Statistical Analyses

For each participant, we summed ability scores from their two ACED interviews for the correlation analyses. To evaluate the distribution of the ACED scores, we averaged the scores of each ability from the two ACED interviews and rounded the mean values to the nearest whole number, preserving the 2, 1, or 0 scoring scale. To measure inter-scorer reliability we calculated an intraclass correlation coefficient (9) and internal consistency reliability with a Cronbach alpha.

To examine validity, we used the Spearman's rank correlation coefficient (r_s) to evaluate associations between ACED ability scores and demographic characteristics, cognition, and the MacCAT-T ability measures. Our hypotheses were that ACED scores should have a strong correlation with measures of cognition and medical decision-making capacity. We defined an $r_s > 0.5$ as a strong effect size and an r_s between 0.3 and 0.5 as a moderate effect size. (10) All analyses were performed using SAS 9.1 (SAS Institute, Inc., Cary, NC) and STATA 8 (Stata Corporation, College Station, TX).

RESULTS

Patients ($n=39$) had a mean age of 81, and 36 (92%) had a diagnosis of dementia. Forty-nine (94%) of the 52 total participants were White race; patients and caregivers reported similar years of education, with means of 13 and 15 years, respectively. With a mean age of 81, patients were older than caregivers (mean age 62). Except for the test of verbal fluency, patients also demonstrated lower performance on cognitive tasks relative to the caregivers based on their average raw scores.

Reliability of the ACED

Among a subset of participants (n=15), two trained interviewers showed good inter-scorer reliability for each decision-making ability, with intraclass correlation coefficients of 0.72, 0.69, and 0.65, respectively, for understanding, appreciation, and reasoning. Percentage agreement for choice was 93%. For patients and caregivers combined (n=52), the internal consistency of the ACED abilities was also good, with Cronbach alpha values of 0.92, 0.88, and 0.84, respectively, for understanding, appreciation, and reasoning.

Distribution of ACED Ability Scores

Table 1 juxtaposes patients' and caregivers' ACED scores for each of the four decision-making abilities. Both groups were equally capable of articulating a choice. They differed in their abilities to understand, appreciate, and reason. Only 15 patients (38%) achieved an understanding score above the lowest score observed in the caregiver group. Six patients (15%) scored in the highest category (7–8) for appreciation, whereas, all caregivers scored within the highest category. The majority of patients, 29 of 39, scored between one and four. Contributing to the lower scores was notably poor performance on the appreciation item asking patients whether they thought they had the functional problem: 22/39 patients (56%) demonstrated inadequate (score=0) recognition of proxy reported functional problems. Performance on reasoning ability was similar to appreciation, with only six patients (15%) achieving scores in the highest range (9 or 10). We observed total scores above five points in this ability for 30 patients (77%), reflecting the higher scores found from questions testing comparative reasoning and logical consistency.

Correlates of Everyday Decision-making Performance

Among the 39 patients, we observed no significant correlation between ACED performance in understanding, appreciation or reasoning ability, and the variables of age, gender, or education level (spearman correlations (r_s) ranged from -0.18 to 0.22 , all $p > 0.16$). In contrast, MMSE scores had a moderate to strong correlation with all three decision-making abilities ($0.48 \leq r_s \leq 0.60$, all $p < 0.002$). Among the three measures of executive function, the Trails B and COFL showed a moderate association with ACED understanding and reasoning performance ($0.33 \leq r_s \leq 0.59$, all $p < 0.04$). All three tests demonstrated no correlation with ACED appreciation scores ($0.06 \leq r_s \leq 0.25$ $p > 0.08$). Each ACED ability measure was associated with its corresponding measure on the MacCAT-T: appreciation $r_s = 0.38$ ($p = 0.02$), reasoning $r_s = 0.50$ ($p = 0.001$), understanding $r_s = 0.63$ ($p < 0.001$), and expressing a choice $r_s = 0.71$ ($p < 0.001$).

CONCLUSIONS

Based on its reliability, scoring pattern, and associations with measures of cognition and the MacCAT-T, the ACED is a valid measure of everyday decision-making ability. The unique content focus of the instrument allows it to be useful for assessing the capacity of older persons with very mild to moderate cognitive impairment to make decisions about how to manage their IADL disabilities.

The ACED fills an important shortcoming of existing instruments. (1) In cases where patients demonstrate deficits in IADL function and cognitive ability, the ACED provides a patient specific assessment of decisional abilities. This may be useful in the syndrome of self-neglect, where patients may refuse assistance with IADLs. Although the presence of preserved capacity to make these decisions means that clinicians should respect their patients' choices, these patients ought to receive a high degree of surveillance. This may involve frequent reassessments of capacity and preemptive legal and financial planning based on clinical

judgment. This is particularly true for those with neurodegenerative dementia, where the natural course often leads to a complete loss of decision-making capacity.

Our data also highlight the value of measuring the four decision-making abilities. Capacity based solely on the ability to express a choice and reason about that choice would be the simplest approach but also the most misleading. Patients in our sample were generally able to make a choice and reason through it. Assessing ACED understanding and appreciation as well would help to more accurately identify patients with preserved capacity.

Limitations include the modest sample size and the varied etiologies of our sample's cognitive impairment which limit the generalizability of our results to specific diagnostic groups. Nonetheless, the diversity of our sample suggests that the ACED may be capable of characterizing everyday decision-making ability among persons attending a geriatrics clinic. The cross-sectional data temper conclusions about causality.

Acknowledgments

Acknowledgement of Support: This work was supported by the Robert Wood Johnson Foundation, the NIA (T32AG1934 (JML), K24AG021507 (TMG), P30-AG10124 (JHK)), the Alzheimer's Association (IIRG-05-14532 (KAH)), the Donaghue Foundation (#02-102 (EHB)), a Greenwall Faculty Scholar Award (JHK), and the Ware Alzheimer Program (JHK).

References

1. Lai JM, Karlawish J. Assessing the Capacity to Make Everyday Decisions: A Guide for Clinicians and an Agenda for Future Research. *Am J Geriatr Psychiatry* 2007;15(2):101–111. [PubMed: 17272730]
2. Loeb, PA. Independent living scales (ILS) manual. San Antonio: Psychological Corp; 1996.
3. Tierney MC, Charles J, Naglie G, et al. Risk factors for harm in cognitively impaired seniors who live alone: a prospective study. *J Am Geriatr Soc* 2004;52(9):1435–41. [PubMed: 15341543]
4. Folstein MF, Folstein SE, McHugh PR. "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res* 1975;12(3):189–98. [PubMed: 1202204]
5. Grisso, T.; Appelbaum, PS. Assessing competence to consent to treatment: a guide for physicians and other health professionals. New York: Oxford University Press; 1998.
6. Karlawish JH, Casarett DJ, James BD, et al. The ability of persons with Alzheimer disease (AD) to make a decision about taking an AD treatment. *Neurology* 2005;64(9):1514–9. [PubMed: 15883310]
7. Lezak, MD. Neuropsychological Assessment. Vol. 3. New York: Oxford University Press; 1995.
8. Marson DC, Chatterjee A, Ingram KK, et al. Toward a neurologic model of competency: Cognitive predictors of capacity to consent in Alzheimer's disease using three different legal standards. *Neurology* 1996;46(3):666–72. [PubMed: 8618664]
9. Shrout PE, Fleiss JL. Intraclass Correlations - Uses in Assessing Rater Reliability. *Psychological Bulletin* 1979;86(2):420–428. [PubMed: 18839484]
10. Cohen, J. Statistical power analysis for the behavioral sciences. Hillsdale, N.J: L. Erlbaum Associates; 1988.

Table 1
Performance of patients and caregivers on measures of everyday decision-making performance

ACED Ability	Patients, n = 39		Caregivers, n = 13	
	n	%	n	%
Ability to understand				
0	5	13	0	0
1–2	3	8	0	0
3–4	9	23	0	0
5–6	7	18	0	0
7–8	6	15	1	8
9–10	9	23	12	92
Mean (SD)	5.2 (3.2)		9.8 (0.6)	
Ability to appreciate				
0	1	3	0	0
1–2	13	33	0	0
3–4	16	41	0	0
5–6	3	8	0	0
7–8	6	15	13	100
Mean (SD)	3.5 (2.0)		7.9 (0.3)	
Ability to reason				
0	0	0	0	0
1–2	2	5	0	0
3–4	7	18	0	0
5–6	12	31	0	0
7–8	12	31	0	0
9–10	6	15	13	100
Mean (SD)	6.3 (2.1)		10 (0)	
Ability to express a choice				
0	1	3	0	0
1	0	0	0	0
2	38	97	2	100
Mean (SD)	1.9 (0.3)		2 (0)	

Higher Scores represent better performance on the ability measure