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Mila Rainof

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Do Caregivers Accurately Assess the Decision-making  
Ability of their Cognitively-Impaired Relatives?

A Thesis Submitted to the  
Yale University School of Medicine  
in Partial Fulfillment of the Requirements for the  
Degree of Doctor of Medicine

By  
Mila Rainof  
Class of 2008

**Abstract****DO CAREGIVERS ACCURATELY ASSESS THE DECISION-MAKING ABILITY OF THEIR COGNITIVELY-IMPAIRED RELATIVES?**

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Although caregivers are often faced with determining whether their relatives have the decision-making ability to solve everyday functional problems, it is unknown whether caregivers' immediate opinions reflect more formal clinical assessments. In this study, we examine whether caregivers' assessments of decision-making ability are consistent with measurements of decision-making ability using the Assessing Capacity in Everyday Decision-making (ACED). This study was cross-sectional, performed in an outpatient specialty clinic. For 39 patients with mild to moderate cognitive impairment, we asked caregivers a series of questions about the patient's overall and specific decision-making ability. Responses were scored on a five-point Likert scale. We measured patient decision-making ability using the ACED instrument. In our analysis, we examined the correlates of caregiver perceptions and determined its relationship with measured decision-making ability using multivariate linear regression. The Spearman correlation coefficients between all caregiver perceptions of patient decision-making ability and ACED scores were less than 0.24 ( $P > .13$ ). Multivariate analyses, adjusting for the time the caregiver spent with the patient, showed a non-significant relationship between the caregiver perceptions of decision-making as compared to the ACED and the amount of time the caregiver and patient were together. Caregiver opinion may not be reflective of actual measures of decision-making ability. Broader use of objective instruments may be needed to help accurately identify impaired decision-making ability. Disagreement between caregivers' Likert scoring and ACED scores was not predicted by the amount of time the caregiver spent with the patient or by patient or caregiver gender. Caregivers were more likely to underestimate patient decision-making in the categories of meal preparation, medication administration and overall. They were equally likely to over- and underestimate patient decision-making in the category of finances. The caregiver's relationship to the patient likely affects the likelihood of underestimation of decision-making ability, although this study was not large enough to confirm these results.

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## **Introduction**

The conference room falls eerily silent. The sound of twiddling thumbs is nearly audible as several of the interns at morning report stare at blank spots on the wall to avoid eye contact with the lecturer, who awaits a simple answer to a not-so-simple question:

“Would you send this elderly cognitively-impaired woman home?”

The lecturer has spun a common story, the kind that is well-known to all members of the medical staff. There is an elderly lady with a 27/30 on her MMSE (Mini-Mental State Exam) who allegedly has made some poor choices recently. She is not quite sure when she last took her diabetes medications. She is adamant about going back to live by herself in her own home, stating that she makes careful decisions about her medications, meals and finances, but her physicians are unsure whether her judgment in the everyday setting is sound.

The physicians note that the patient’s daughter is sitting in the room with her. With limited clinical measurements available and even more limited time in a busy hospital to answer the question at hand, is it reasonable for them to simply ask the daughter: “can your mother make good decisions?” Are family members accurate in their assessments of decisional capacity in their cognitively impaired relatives?

Although the scenario above and the question it poses are common, the clinical assessment measures needed to come to a solution are not at all clear. There is currently no standard practice to determine decision-making capacity in cognitively impaired elderly people (1). By 2050, it is expected that the number of people with Alzheimer's disease will triple from the year 2000, reaching 13.2 million. The number of people who are 85 years and older will quadruple to 8.0 million (2). Clearly the need for reliable measurements of every day decision-making ability is increasingly urgent, and the role of the patient's relatives and loved-ones in this process is bound to be central.

While the physician bears a responsibility of suggesting the best course of action for treatment, and, often for living arrangements, it is ultimately the caregiver who is immediately responsible for looking after the patient on a daily basis. This situation begs the question of whether or not caregivers have an accurate appreciation of the every day decision-making capacity of their elderly family members.

### *Everyday Decision-Making*

Everyday decision-making refers to the ability of a person to make good choices in his or her daily life. It does not refer to the medico-legal term "competency," which has a broad base of research in the literature and refers to the ability to make decisions in the setting of formal medical, treatment and end-of-life questions and their legal ramifications.

Everyday decision-making research is sparser in the literature, but its conclusions are nevertheless proving to be crucial in patient care and the interest in the field of decision-making has therefore been increasing (1). The ability to assess everyday decision-making capacity is central to patient autonomy and to what degree autonomy can be compromised in the interest of safety. This assessment is always complicated, given that cognitive impairment does not directly translate into decisional impairment (3) — a cognitively-impaired patient can very well be capable of holding and expressing a very reasonable opinion regarding his or her own well-being. Additionally, patients who are only mildly cognitively impaired may in fact have deficits in their ability to perform activities of daily living (ADLs) (4, 5, 6, 7, 8). If one overestimates a patient's decision-making ability and places too much independence in the patient's hands, the patient could actively harm himself by accident or could harm himself indirectly by neglecting to meet his everyday needs. Medications must be taken, food must be cooked, and finances must be managed. However, if one underestimates the patient's decision-making capacity and allows proxies to have more surrogate decision-making power over the patient than is necessary, the patient's autonomy is compromised and perfectly acceptable preferences could be ignored.

### *Tests of Decision-making*

Decision-making is in fact a very central component of a patient's ability to perform his or her ADLs and instrumental activities of daily living (IADL). For an individual to perform his or her ADLs and IADLs, he or she must not only be physically capable of performing the task at hand or of accepting the help needed to perform them if physically



unable to do so, but also capable of making sound problem-solving decisions regarding how, when and why to perform the task. For example, an elderly person who is perfectly capable of cooking may for various reasons make poor decisions about when and what to eat, resulting in malnutrition if he or she does not cook often enough or eats nothing but jelly beans for a month. Given that decision-making plays such a central role in the performance of everyday activities, assessment of everyday decision-making is necessary for many different healthcare management considerations. For example, discharge planners must determine the amount of aid that patients will need once discharged from the hospital (9). The patient's ability to perform his or her ADLs and to make decisions regarding those ADLs is a large consideration. If a patient lives at home independently, home nursing may be required or it may be determined that the patient can no longer care for himself and must be placed in a nursing facility. If a patient is already a resident in a nursing home, the level of care expected from the nursing home and the financial reimbursement by Medicare is based in part on a patients' dependence in ADLs and their ability to regain their independence in them. The assessment of this is done using the Minimum Data Set (MDS), which is a government-mandated form of documentation of everyday needs and medical complications. The MDS is conducted largely through subjective means, using observation by nursing staff and informants (2). Although the implications of the MDS are extensive, the MDS itself is not based upon objective fact and ends up leaving much to opinion (9).

This lack of reliability in decision-making capacity measurement is very pervasive.

Despite the fact that everyday decision-making measurements in cognitively impaired

adults is so critical to healthcare management, there is currently no consistently applied instrument to objectively measure it. Most instruments for decision-making are directed towards assessing legal competency, treatment decisions and participation in medical research (10, 11, 12). For example, the MacArthur Competence Assessment Tool-Treatment (MacCAT-T) was developed as a clinical, easy-to-use tool for evaluating competency to consent to treatment (11). The MacCAT-T assesses legal decision-making ability by dividing competence into four components: Understanding, Appreciation, Reasoning and the Ability to express a choice. Although tests like the MacCAT-T are effective in determining questions of competency in clinical settings, they are designed for those settings in mind and do not include questions directed towards everyday decision-making. They cannot be assumed to be indicative of everyday decisional capacity.

The most common test to assess cognitive impairment is the Folstein Mini-Mental State Exam (MMSE) (13). The MMSE, created in 1975, is very easily and widely administered; it usually takes about 10 minutes, with a total score out of 30 points. It tests language, memory, visuo-spatial skills and simple praxis, making it an excellent test for determining the existence or degree of parietal lobe impairment in a patient. To some degree, the MMSE has been shown to correlate with decisional capacity (1). However, the MMSE does not contain any questions that directly pertain to decision-making nor does it test many of the cognitive functions needed for decision making, much less everyday decisional skills; for that reason its results are not sufficient in assessing a patient's everyday decisional capacity.

Another common test is the EXIT examination (14). Introduced in 1992, the EXIT examination is used specifically to test executive function at the bedside. It is a 10-minute 25-question interview scored out of 50 points. The EXIT exam correlates with frontal-lobe dysfunction, reflecting executive function, or some of the higher level cognitive processes needed for problem solving behaviors. Although these higher level functions correlate better with decisional capacity, this measurement of general executive function is not a direct measurement of decision-making ability and cannot be used to substitute for more specific measurements. Other tests of executive function include the Trails A and B (15), and the Controlled Oral Word Fluency Test (COFL) (16).

Some decisional capacity instruments have been created to look at everyday problems, but many of them are difficult to apply or conduct. Many of them rely upon hypothetical situations, leaving much room for subjective interpretation as to how their results bear upon real-life situations. One of the only instruments directed towards everyday decision-making is the Decision-Making Instrument for Guardianship (DIG) (17). As its name suggests, this tool was created to assist the legal system in guardianship questions. It consists of eight hypothetical everyday problems concerning hygiene, nutrition, health care, residence, property acquisition, routine money management in property acquisition, major expenses in property acquisition, and property disposition. It requires patients to abstract how they would act if they were put in these situations. This hypothetical format makes the DIG quite difficult to apply to real life (9). It is unclear whether the test measures a patient's ability to abstract or his ability to make decisions regarding that

abstract concept. The test is also confounded in that correctness of response can be experience-based, as a patient who has had a situation similar to the hypothetical condition posed may perform better, as he or she may be able to use additional information from his own personal experience base. Additionally, the DIG does not give the clinician any insight as to the degree to which the patient appreciates the relevance of the question at hand to his own situation. This concept is important, because a patient's insight into a situation can be indicative of his or her prognosis for further cognitive decline (18).

Some tests address performance on IADLs and ADLs, measuring patient judgment and/or functional capacity (19). Unfortunately, these tests also rely upon hypothetical situations. The Problems in Everyday Living Test (20) has been shown to be a closer reflection of patient ability to perform IADLs as compared to the MMSE. The Everyday Problems Test (21) and the Everyday Problems Test for Cognitively Challenged Elderly (22) were designed to assess elderly patients' judgment regarding and ability to work through hypothetical situations involving complex tasks of daily living, particularly IADLs. As instruments, they were created to reflect global cognitive and also executive functions. Although effective in measuring some aspect of performance on IADLs, these tests' results are difficult to apply and interpret in relation to real-world situations because the patient is required to abstract hypothetical situations that may or may not relate to his own situation at hand. It is unclear whether results would represent ability to abstract or actual IADL performance.

Some tests of everyday problem solving are clinically applicable, but have other limitations. The Financial Capacity Instrument (23) uses 14 tasks of financial ability comprising 6 domains: basic monetary skills, financial conceptual knowledge, cash transactions, checkbook management, bank statement management, and financial judgment. It was shown to separate mild dementia from moderate dementia, and accurately pinpoint financial deficits. However, although this test addresses one everyday problem quite well, it can be unwieldy and time consuming. Additionally, it is limited to the question of finances and cannot be applied to everyday decision-making at large. The Alzheimer Disease Cooperative Study (24) uses everyday clinical scenarios to measure patient ADL performance, but the interview is time-consuming and requires proxy input rather than direct measurements. It also fails to distinguish decision-making capacity from physical capacity to perform ADLs.

In this study, we used Assessing the Capacity to Make Everyday Decisions (ACED) as an objective measurement of decision-making capacity (9, 25). It applies the format of the MacCAT-T to everyday decision-making scenarios. A recently validated instrument, it has shown good inter-scorer reliability with intra-class correlation coefficients of 0.72 for Understanding, 0.69 for Appreciation, and 0.65 for Reasoning. The percentage agreement for choice was 93%; internal consistency was demonstrated by Cronbach alpha values of 0.92, 0.88 and 0.84 for Understanding, Appreciation and Reasoning respectively (25). It does not use hypothetical situations, but rather employs situations that are actually relevant to the patient and explores how the patient operates within these scenarios. The ACED uses a semi-structured interview in different categories such as meal preparation,

finances and medication administration (see Table 1). Scenarios are chosen based upon the actual known functional problems the patient faces. There are four components to the ACED: Understanding, Appreciation, Reasoning and Expressing a Choice. In the Understanding section, the patient is told the scenario and must explain the nature of the problem and its possible consequences. The Appreciation section is designed to test for insight, as the patient must discuss how the scenario described relates to his or her own deficits. In the Reasoning section, the patient is given several solutions to the problem and asked to make an initial choice. He must compare the choices at hand and explain why he prefers the option he selected. He must also describe the benefits and harms of the solutions offered. Finally, the patient must express a choice. A brief explanation is required, and the tester looks for logical consistency with the patient's initial choice and his final choice. Most patients can complete the final step (Expressing a Choice), with inability to do so being indicative of more severe dementia.

The ACED was chosen for this study because it is easy to administer, and time-conservative. It also avoids the primary drawback of many other instruments in that it does not use hypothetical situations. Instead, it uses actual problems that the patient is known to face and therefore tests for real-life decision-making ability for a directly applicable scenario, without the confounder of asking the patient to understand the abstraction inherent in a hypothetical situation. The ACED uses a proven framework as it is based upon the MacCAT-T, which has been shown to be effective in providing objective information about ability to consent for treatment. When using the ACED, one must keep in mind that it has been validated only very recently and is a very young test. It

will likely evolve as more complex situations are introduced over time and it is adapted to be applicable in unforeseen circumstances. Additionally, direct monitoring of patients actual performing the tasks tested by the ACED would further aid in validation of the instrument, but these tests have not yet been performed.

### *The Use of Proxies*

For convenience and because there is no established instrument currently used to measure decision-making in the cognitively-impaired, other sources are often relied upon. One of the most commonly-used sources of information about a cognitively-impaired patient is the knowledgeable informant (9). A knowledgeable informant is a relative or caretaker such as a partner or an adult child who spends time with the patient and has some understanding of the patient's habits and abilities. It is easy to understand why the knowledgeable informant is referred to so frequently when there is a question about the patient's capacity. Knowledgeable informants are very convenient sources of information, they often spend sustained amounts of time with the patient, see the patient in their own environment and they can give physicians insight into the patient's condition and actions. The degree to which they are reliable, however, is a subject of some discussion — though proxy accuracy has never been examined in relation to decision-making ability, it has been extensively researched in relation to other aspects of cognitive impairment.

Some studies have found proxy input to be very reliable (26, 27, 28, 29, 30, 31) and have used knowledgeable informant input as the gold standard by which to measure various

cognitive impairment parameters (29). For example, Dementia Severity Scale (DSS) is a validated tool that measures ability to perform ADLs, behavioral changes, and cognitive ability through a survey-style interview of the patient's caretaker (26). The Dementia Deficits Scale (DDS) also uses caregivers' input and has been compared with physician and patient perspectives, concluding that caregivers yield unique, reliable and invaluable information (30). Family members have also performed reliably when it comes to scoring their loved ones' memory abilities, as these scores have been shown to be consistent with objective clinical measures (28). Some studies indicate that informants are very accurate in their overall perceptions of cognitive (27) and personality (31) changes in their family members.

There are, however, many grey areas in which similar studies come to opposite conclusions. One area in which this contradiction is particularly evident is in quality of life rating for the cognitively-impaired. Although one study has shown that quality of life ratings by proxies is consistent with the frequency of positive facial expressions and negative facial expressions in patients (32), it is countered by another study in which patients' own description of their quality of life varied substantially from that described by their caretakers (33, 34). The difference in the results of these two studies likely stems from the fact that "quality of life" can be defined, perceived and measured in very different ways. Measuring affect frequencies is very different from directly asking patients about quality of life, which could partially explain the variety of conclusions yielded in different studies. Additionally, these studies were performed in patients with differing severity of cognitive impairments. The lack of standard measurements and



definitions is unfortunately a theme in studies of caregiver perceptions of cognitively-impaired patients, and it makes consistency and comparison between studies quite difficult.

While there are a number of studies that support caregiver reliability and a handful that provide ambivalent results, the majority of studies strongly conclude that caregiver assessments of cognitively-impaired patients are often inaccurate (34, 35, 36, 37, 38, 39, 40, 41, 42, 43, 44). For example, caregivers have been shown to inaccurately describe the degree of patient depression (39). As depression can commonly masquerade as worsening of Alzheimer's Disease and vice versa, such a misperception could in fact be very confusing and damaging, as depression and worsening Alzheimer's must be managed differently and have different prognoses. At the legal level, caregivers and guardians have been shown to inappropriately define patient competency (43), at least partially due to a deficit in understanding of the criteria. Caregivers have also been shown to consistently underrate the physical capability of cognitively-impaired patients (45). There have been shown to be significant discrepancies between instrumental measurements and caregiver perceptions of patient abilities to carry out ADLs (35, 37, 38, 44). Studies have shown that significant others (46) and other caregivers (41) consistently underestimate ADL and functional ability as compared to professional medical staff evaluations. Proxies can both over- and under-estimate patient ability to meet everyday financial needs (42). As decision-making is a component of ADL performance, the fact that proxies tend to incorrectly evaluate ADL performance gives reason to suspect that they might be equally inaccurate in describing decisional capacity.

Although it seems that the trend is towards underestimation, there is one scenario in which overestimation is more common. It is not surprising to discover that proxy impressions of patients depend upon particular patient attributes. In situations where patients are only mildly cognitively impaired with higher MMSE scores, caregivers consistently overestimate a patient's ability to perform ADLs (36, 38). Mildly cognitively impaired patients can compensate for their deficits more effectively, and can thereby mask their limitations. However, there is one exception to this rule of overestimation in cases of mild cognitive impairment. If the caretaker of a mildly-cognitively-impaired patient is depressed or perceives his caregiving burden as extensive, he or she may be more likely to underestimate the ADL abilities of the patient (47, 34), although this connection is by no means certain and has been contested (48). In these cases of mild cognitive impairment and its resultant ambiguity, caution and an objective measurement of patient functional and decision-making capacity are particularly important.

Just as patient attributes can impact how caregivers perceive patient decision-making ability, the attributes and demographics of caregivers themselves are also important in shaping caregiver perceptions. Caregiver depression is a very well-studied and is a prevalent concern (49). It has been shown to negatively bias caregiver impressions of a patient's functional ability as compared to direct medical observation and instrumental measurements (48, 34, 44). As many as 32% of caregivers of cognitively-impaired patients experience clinical depression (50). The concept of caregiver depression is inextricably bound to another very influential factor — caregiver perceived burden.

Depressed caregivers are more likely to feel overwhelmed by their duties (48, 34, 51) and are therefore more likely to emphasize their caretaking burden, underestimating the degree to which patients can enjoy life and operate independently (47, 34). The consequences of having a caregiver who is feeling overburdened can prove disastrous for a cognitively-impaired patient. Evidence has shown that emotional intervention by caregivers can positively influence the progression of dementia (33). For this reason, caregiver burden and lack of available emotional resources can result in reduced emotional support, diminished overall quality of life and a poorer prognosis for the patient. Not surprisingly, it has also been reported that this poor patient quality of life can lead to poor caregiver quality of life as well, and vice versa (51), magnifying the problem at hand. To make matters worse, burdened and depressed caregivers often conclude that the quality of life of their care receivers is even worse than it is in reality (47, 34), a fact which also multiplies the negative effects of caregiver burden. If caregivers who have an increased burden hold a generally skewed view of their loved ones and their abilities, it stands to reason that caregiver opinion of decisional ability might be similarly inaccurate.

A large, multi-center study of depression (50) in caregivers concluded that caregiver attributes that independently predicted depression include income less than 10,000 dollars per year, higher number of hours spent caregiving (with 79 hours a week or more being highly predictive), and being the patient's wife as compared to being the son of a male patient. In fact, female gender in general has been correlated with caregiver depression (51). The same large study also concluded that there are several patient characteristics that tend to predict caregiver depression and consequent report unreliability. These

characteristics include patient age below 65, lower education level, low ability in ADLs, increased aggression and behavioral problems, and ethnicity. Hispanic and white families members were more likely to become depressed than black family members (50). Other studies have shown that black caregivers generally overrate their relative's cognitive capacity while white caregivers tend towards underrating (52). The reasons for this disparity are unclear. Additionally, degree of patient dependence on the caregiver increases with degree of patient impairment (53, 54); as a result, caregivers of the severely demented (and therefore highly dependent) patients with few community support systems are more likely to rate their burden as extensive, and to become depressed and increasingly inaccurate in their reports of patient ability (55).

Clearly, there are many factors that can lead to caregiver depression and can consequently result in caregiver unreliability and inconsistency in reporting. Depression and burden therefore result in a vicious cycle of decreasing quality of life for everyone involved, and create a negatively-skewed caregiver perspective regarding patient ability. Consequently, one would logically conclude that degree of burden and depression in caregivers must always be considered when evaluating caregiver accuracy. As logical as this assumption might be, it is important to note that the role that depression and burden play in caregiver perception is by no means indisputable. The connection between caregiver depression and perception of patient IADL performance has been contested (35), with authors drawing the conclusion that disparities between caregiver perceptions and actual patient performance were unrelated to any specific caregiver, patient or relationship factor, including degree of frustration with the patient and caregiver

depression. As with all clinical considerations, the individual characteristics of each patient and his or her family must be taken into account when drawing conclusions about health care management.

Proxies have also been shown to be relatively inaccurate as surrogate decision-makers. If the surrogates always made decisions that reflected those of the patient, the situation would be less complicated. Unfortunately, the standards for surrogate decision-making are fairly loose and undefined. Some surrogates make decisions that they feel are in the best interest of the patient, while others choose to use “substituted judgment,” wherein they imagine what the patient would want and they advocate that decision (56). There are problems with both of these approaches. It is often unclear what the patient’s “best interest” may be, especially if the patient’s wishes run counter to the perceived best interest, as is the case with many end of life issues. In matters of substituted judgment, many surrogates are actually inaccurate in their assessment of what the patient would want (18). There are also times when a surrogate who knows the patient well, such as a family member or friend, is unavailable. In these cases, it can be very challenging to find a proxy who can act on the patient’s behalf in an effective manner, especially as this may end up being a court-appointed conservator — for all practical purposes, a stranger (57). Therefore, an accurate assessment of everyday decision-making must be made to minimize reliance on surrogates and consequent loss of autonomy.

Clearly, steps need to be taken to better assess the decision-making capacity of cognitively-impaired patients. Surrogates are not ideal, measurement instruments are not

widely implemented, and the degree to which proxies understand the decision-making capacity of their cognitively-impaired loved ones remains a subject of much debate, given that many different variables can skew perception. As the input of relatives seems to be one of the most commonly-used sources of information about the decisional capacity of the cognitively impaired adult, its accuracy must be further investigated.

### **Statement of purpose: hypothesis and specific aims of the thesis**

#### *Hypothesis:*

Caregivers estimates of a patient's ability to make every day decisions will differ significantly from an objective measurement of the patient's abilities produced by the ACED.

#### *Specific aims*

In comparing an objective measure of decision-making capacity to the perceptions of caregivers, this study seeks to better define the reliability of caregiver opinion as regards the decision-making capacity of loved ones. Given the fact that caregivers are most commonly the source of such information, the degree to which their opinions correlate with other measures is vital information. This study seeks to investigate whether caregivers overestimate, underestimate or correctly estimate the decisional capacity of their elderly loved ones as compared to the patient's ACED scores. This study will also look at confounding factors such as the number of hours spent with the patient,

relationship to the patient, MMSE score of the patient and gender of the patient and caregiver.

## **Methods**

### *Design*

The design of this study is cross-sectional, and was part of a larger study performed by Dr. James Lai, in which he examined the validity of a new test for decision-making capacity, Assessing Capacity in Everyday Decision-Making (ACED). The author proposed the study design and original study idea. The ACED was measured in conjunction with the following exams to test its concordance with them: Instrumental Activities of Daily Living (IADL) function, Mini-Mental Status Exam (MMSE), Trail-Making Test – Parts A and B, Controlled Oral Word Fluency Test (COFL), Insight, Decision-making In Guardianship (DIG), and Functional Assessment. It was recently validated and showed good inter-scorer reliability (25). The ACED is scored out of 30 possible points. It provides a score of competency in the following four categories of decisional capacity: Understanding (10 points possible), Appreciation (8 points possible), Reasoning (10 points possible) with sub-categories of consequential and comparative reasoning, and Expressing a Choice (2 points possible). Patients must show an understanding of their options, and of the harms and benefits of their choices in order to gain points (see Table 1).

### *Subjects*

Thirty-nine subjects were drawn from the Adler Center Outpatient Geriatric Assessment Center at Yale-New Haven Hospital in New Haven, Connecticut. Charts were screened for 268 subjects, of which 119 were eligible. Of those, 42 subjects were approached to participate in the study and three refused. Thirty-seven interviews were conducted at the patient's home setting, and two interviews were conducted in the clinic. Inclusion criteria were: the patients must be 60 or older, reside in the community or in an assisted living facility, able to complete a Rapid Estimate of Adult Literacy in Medicine (REALM) literacy instrument exam (58), and possess at least one IADL deficit in meal preparation, management of finances, or medication administration as identified by the caregiver. Eligible patients had to be accompanied by a knowledgeable caregiver. Exclusion criteria were; patient residing in a nursing home or other long-term care facility, hearing or speaking deficiencies, active delirium or acute psychosis, an MMSE less than 12, or non-English speakers. Patients had to have a proxy for consent. This study was approved by the Human Investigations Committee at Yale School of Medicine.

### *Management*

Direct decisional capacity of patients was measured using the ACED and the other instruments described above. The total testing process for the patients required one hour and thirty minutes. Caregivers were interviewed by a separate tester, using a survey of twelve questions written by the author which took approximately fifteen minutes to administer. The author administered the questionnaire for the development of this study during the pilot, and Dr Lai and his assistant administered the questionnaire for the



patients included in this study's results. The questions explored caregiver perceptions of patient decision-making ability in everyday situations. Questions focused on the areas of general decision-making, everyday financial decisions, meal preparation, and medication administration. Questions contained overlapping content with different framing to maximize accuracy of responses. Responses were given according to a Likert Scale ranging from 1-5, with 1 being highly unlikely and 5 being highly likely to be capable of making correct decisions. A "Don't Know" category was also included. The questions were as follows:

#### GENERAL

1. What is the likelihood that your spouse/relative's decision-making ability is as good as yours?
2. Do you think that your spouse/relative could make appropriate every day decisions about his/her health by himself/herself? (For example, seeking help for a problem.)
3. How likely would a decision made by your spouse/relative in his/her daily activities result in a serious injury to himself/herself or someone else?

#### FINANCES

4. What is the likelihood that your spouse/relative is making appropriate decisions about his/her day to day finances?
5. What is the likelihood that your spouse/relative is making decisions about handling his/her money as well as you do?
6. How likely is it that your spouse/relative would make a financial decision that would result in a serious mistake or the loss of money?

#### MEAL PREPARATION

7. What is the likelihood that your spouse/relative is making appropriate decisions about when and what type of food to prepare each day?

8. How likely is it that your spouse/relative would suffer an injury while operating a kitchen appliance?

#### ADMINISTRATION OF MEDICATION

9. What is the likelihood that your spouse/relative would make appropriate decisions about managing his/her medications without any assistance?

10. What is the likelihood that your spouse/relative would choose the wrong dose or take the wrong medication without any help?

11. What is the likelihood that your spouse/relative would be able to come up with a system to help her take her medications on time and at the correct doses?

12. What is the likelihood that your spouse/relative would safely decide when to self-administer over-the-counter medications (such as Tylenol)?

#### *Statistics*

Dr Lai performed half of the statistics for this study, and the author performed the other half, mostly focusing on caregiver characteristics. In our analysis, we examined the correlates of caregiver perceptions and determined their relationship with decision-making ability as measured by the ACED using multivariate linear regression, adjusting for time spent with the patient. The total ACED score (0-30) for all four sections was compared to the average Likert score for each of the twelve questions, using  $r$  correlation to measure the degree of agreement. A  $p$ -value for each correlation was also calculated.

The relationship between the caregivers' Likert scores of patient decision-making ability and ACED score was examined in each category: medication administration, meal preparation, finances and overall decision-making ability. Questions representative of each category were picked for this comparison, which included questions 1, 6, 7 and 9 from the caregiver questionnaire. Some questions asked about the likelihood of patient harm while others questions asked about likelihood of good patient judgment, and the direction of the Likert score had to be adjusted accordingly. For example, in the case of a likelihood-of-harm-based question, a 4-5 response meant that the caregiver felt that the patient was likely to cause harm to himself and therefore exhibited poor decision-making. However, in a likelihood-of-safety-based question, a 4-5 response meant that the patient was more likely to stay safe, indicating good decision-making. "Overestimation" by the caregiver was defined as a score of 10 out of 30 or less on the ACED compared with a caregiver response of either 4 to 5 or 1 to 2 on the 5-point Likert scale, depending upon the phrasing of the question "Underestimation" was defined as a score of 20 or more out of 30 on the ACED as compared with a caregiver score of either 4-5 or 1-2 indicating an increased likelihood of harm.

T-tests were used to calculate statistical significance for patient MMSE score and hours spent with the patient for caregivers whose responses did and did not correlate with the ACED scores. Simple percentages were used to assess which gender and relationship to the patient were more likely to rate patients high or low on the caregiver scale as compared to ACED score.

## Results

Patients included in this study (Table 2) had an average age of 81 years, with 59% females. Sixty percent of knowledgeable informants were female. Fifty-one percent of patients were previously diagnosed as depressed as per their medical records. Most patients (95%) were Caucasian. Average patient MMSE score was 22 +/- 4 with scores ranging from 13 to 29.

Ninety-four percent of caregivers felt that the patient's decision-making ability was worse than their own. Thirty-four percent of caregivers believed that there was a high likelihood that a decision made by the patient would result in a serious injury (Table 3, Table 4). Caregivers were most likely to consider patients incapable of good decision-making in the category of medication administration, with an average of 82% of caregivers stating that it would be unlikely for the patient to make good decisions when taking medications. An average of 77% of caregivers felt that the patient would be unlikely to make good decisions in finances. This percentage was comparable to that in the category of meal preparation, where 76% of caregivers felt that the patient would be unlikely to make good decisions. When asked general questions about patient decision-making, an average of 74% of caregivers felt that the patient would be unlikely to make good decisions.

The Spearman correlation coefficients between all caregiver perceptions of patient decision-making ability and ACED scores in the categories of understanding,

appreciation and reasoning were less than 0.24 ( $P > .13$ ) indicating very poor correlation. Multivariate analyses showed no relationship between overall caregiver perceptions of decision-making and measured ACED scores of decision-making ability. Poorest agreement between caregiver response and ACED score was illustrated by the following questions: what is the likelihood the patient would make a financial decision resulting in a serious mistake? ( $p = 0.73$ ) and what is the likelihood the patient would suffer an injury while operating a kitchen appliance? ( $p = .90$ ) (Table 5). Agreement between the ACED and the knowledgeable informant rating were significant for three of the questions asked: the likelihood that the patient would choose the wrong medication or dose ( $p = .02$ ), the likelihood that the patient would come up with a system to take his/her medications properly ( $p = .02$ ), and the likelihood that the patient is making decisions about handling his/her money as well as the caregiver ( $p = .04$ ) (Table 5). A negative correlation coefficient resulted for the question regarding likelihood of the patient choosing the wrong medication or dose ( $r = -0.39$ ). This negative  $r$  value indicated that the question was phrased in a manner that reversed the meaning of the Likert scale, as most questions were based upon likelihood of safety but the question above was based upon likelihood of harm. Thirteen out of 39 of the caregivers gave Likert scores inconsistent with ACED scores at least once on any question.

In the category of finances, a 5 on the caregivers' Likert scale indicated poor decision-making and a 1 indicated good decision-making. There were three caregivers who indicated scores of 1-2 on the Likert scale (good decision-making) regarding relatives who scored 10 or less on the ACED (Table 6). All three were males giving opinions

about female patients. Two were husbands and one was a son. Of these caregivers who gave positive decision-making scores as compared to the ACED in the category of finances, hours spent with the patient per week ranged from 6-68 and patient MMSE scores ranged from 19-25, compared with ACED scores ranging from 6-10. There were four caregivers who negatively rated their relatives' decision-making as compared to ACED scores in the category of finances (Table 6), two of which were male and two of which were female. Of the four, two were wives, one was the son of a male patient, and one was a husband. Three out of four of the patients were male. Hours ranged from 40 to 168 per week. MMSE scores ranged from 22-29 and ACED scores ranged from 20-29. ACED score for patients scoring a 5 (poor decision-making) on the caregiver's Likert scale ranged from 0 to 22 (Figure 1) in the category of finances.

In the category of meal preparation, there were no caregivers who gave positive decision-making scores (in this case, a score of 1-2) as compared to ACED scores. There was only one caregiver who gave negative decision-making scores on the Likert scale as compared to the ACED score (Table 6), a daughter spending 70 hours a week with her mother. The patient's MMSE and ACED scores were 25 and 20 respectively. ACED score for patients scoring a 1 (poor decision-making) ranged from 1-18 (Figure 2).

In medication administration, there were also no informants who gave Likert scores that suggested better patient decision-making abilities than the ACED scores indicated. In this case, a rating of 1 on the knowledgeable informant's Likert scale indicated poor patient decision-making in the category of medication administration. ACED scores ranged from

4-25 (Figure 3). Five knowledgeable informants gave negative decision-making Likert scores (4-5) as compared with ACED scores, all of which were female (Table 6). Four were daughters of female patients spending from 17-70 hours per week with the patient. One was a patient's wife, spending 168 hours per week with the patient. There were a total of eleven wives surveyed, with only one underestimating the patient's ability. All of the nine sons surveyed gave Likert scores that were consistent with ACED scores. MMSE scores of patients with comparatively high ACED scores and negative Likert scale scores ranged from 19-27 and ACED scores ranged from 20-25.

For the general decision-making category, ACED scores and Likert scores were gathered in two different categories and then averaged. A score of 1 on the Likert scale indicated poor decision-making. No knowledgeable informant studied rated the patient with a high Likert score as compared with the patient's ACED score. There were six patients with low Likert score ratings by their knowledgeable informants as compared to patient ACED scores (Table 6). There were two daughters of females, one husband, and one son of a male patient, one son of a female patient and one wife. Hours spent with the patient ranged from 17 to 168 per week. The six patients' MMSE scores ranged from 23-28 and ACED scores ranged from 21-25.5. The ACED scores for patients who were given a 1 on the knowledgeable informants' Likert scale ranged from 2-25.5 (Figure 4).

A t-test was performed to compare the number of hours spent with the patient for caregivers whose Likert ratings were consistent with and inconsistent with the ACED. For caregivers who were inconsistent with the ACED (of which there were 13), the mean

number of hours spent with the patient was 83 +/- 72. For caregivers who were consistent, the mean number of hours spent with the patient was 81 +/- 74. The p-value was 0.93.

T-tests were also performed to compare the patients' MMSE scores in situations when caregivers' opinions were consistent or inconsistent with patient ACED scores. For caregivers who felt the patient was more impaired than was indicated by the ACED compared with those whose opinions were consistent with the ACED, the mean MMSEs were 20 +/- 5 and 21 +/- 4 respectively. The p-value was 0.63. For caregivers who felt the patient's impairment was less severe than was indicated by the ACED as compared with caregivers whose opinions were consistent with the ACED, the mean MMSEs were 25 +/- 3 and 21 +/- 4 respectively. The p-value was 0.01. Comparing caregivers who judged the patient as more impaired than the ACED suggested and caregivers who judged the patient as less impaired than the ACED indicated, the p-value was 0.04.



**Table 1.** Example of an ACED structured interview regarding medication administration.

Ability	Questions
Understanding the problem	Q1. "Properly managing your medications is important because, medications are necessary for maintaining your health. Please tell me in your own words what I just told you." Q2. "People who forget to take their medications may end up having a worse health condition and needing more visits to the doctor. Please tell me in your own words what I just told you."
Appreciating the problem	"Do you have any problems remembering to take your medications?" • If she denies having this problem, the interviewer should ask questions to clarify why she thinks this.
Understanding the solutions	"There could be several ways to deal with this problem. Two possibilities are: 1. You could use a pillbox or timer to help you to remember to take your medications. 2. Someone could give your medications to you and watch you take them. Please, tell me in your own words, what I just told you." • If she omits key details, the interviewer may refer her to the information sheet for assistance. This may be done for the Understanding the Benefits/Harms questions as well.
Understanding the benefits and harms	Q1. "There are good things about these solutions: 1. You may have fewer missed medications. 2. You may have less worry about taking the wrong medication. Please tell me in your own words what I just told you." Q2. "There may also be bad things about these solutions: 1. You may lose some independence. 2. You may not know which medications you are taking. Please tell me in your own words what I just told you."
Appreciating the benefits and harms	Q1. "Do you think that having someone give your medications to you and watch you take them could benefit you?" Q2. "Could you think of reasons why these solutions might <i>not</i> help you or even make things worse for you?" • If necessary, the interviewer should instruct the patient to consider the benefits and harms with respect to her own specific situation.
Initial choice	Patient is presented the choice to: 1) use one of the solutions provided, 2) manage her medications alone, or 3) continue what she is doing now. In this case, she chooses to continue what she is doing now (taking her medications on her own straight from the bottle).
Comparative reasoning	"What makes your choice seem better than using a pillbox, timer, and/or calendar to help you to remember to take your medications?" • The interviewer should ask follow-up questions that encourage the patient to explain specifically how one choice is advantageous over another.
Consequential reasoning	"Consider what would happen if you had to have someone give your medications to you and watch you take them. How would this affect your everyday life?" • The interviewer should encourage the patient to provide specific and vivid examples of how her everyday life activities would change as a result of this solution. The patient's answers to the reasoning questions will reveal how she values the potential solutions and weighs the risks and benefits of each.
Expressing a choice	"A few moments ago, you stated that [patient's choice] was your first choice. After having discussed everything, do you still want to do that? Could you explain why?"

<sup>2</sup>The questions are designed as prompts to assess each of the decision-making abilities. The factual content is tailored to the particular decision being assessed. The bulleted items are probes used to clarify answers. To reduce the impact of impairments in short-term memory on interview performance, an information sheet stating the problem, solutions, benefits, and harms can be provided for the patient at the start of the interview.

Courtesy of James Lai, MD. From: Lai JM, Karlawish JH. Assessing the Capacity to Make Everyday Decisions: A Guide for Clinicians and an Agenda for Further Research. *Am J Geriatr Psychiatry*. 2007 Feb; 15(2): 101-111.

**Table 2.** Demographic, Cognitive, and Functional Characteristics of Patients.\*

<b>Characteristics</b>	<b>Patients</b>
	<b>n = 39</b>
Age, years	81 ± 6
Female	23 (59)
Education, years	13 ± 3
White	37 (95)
Diagnosis of Depression	20 (51)
REALM Score	63 ± 4
Cognitive Ability	
Mini-Mental State Exam	22 ± 4
Controlled Oral Word Fluency Test	25 ± 13
Trail Making Test Part A	78 ± 29
Trail Making Test Part B	239 ± 65
ADCS-ADL Activity Score	50 ± 15

\* Values are frequency (%), mean ± SD, or median (range)

**Table 3.** Caregiver Responses to Questions about the Decision-making Ability of Family Members with Cognitive Impairment.

<b>Question</b>	<b>Highly Unlikely</b>	<b>Unlikely</b>	<b>Somewhat Unlikely</b>	<b>Likely</b>	<b>Highly Likely</b>	<b>Don't Know</b>
<b>General, n (%)</b>						
Likelihood pt decision-making as good as yours?	25 (64)	5 (13)	7 (18)	1 (3)	1 (3)	-
Can pt make appropriate decisions about health?	17 (44)	8 (21)	12 (31)	0 (0)	2 (5)	-
Likelihood of pt making a decision resulting in injury?	8 (21)	6 (15)	11 (28)	8 (21)	5 (13)	1 (3)
<b>Medications, n (%)</b>						
Likelihood pt making appropriate DM about managing med?	26 (67)	4 (10)	5 (13)	2 (5)	1 (3)	1 (3)
Likelihood pt would choose wrong med/dose?	1 (3)	3 (8)	5 (13)	4 (10)	26 (67)	-
Likelihood pt come up w/ system to take meds appropriately?	26 (67)	4 (10)	1 (3)	5 (13)	3 (8)	-
Likelihood pt would take PRN meds appropriately?	18 (46)	1 (3)	6 (15)	2 (5)	11 (28)	1 (3)

**Table 4.** Caregiver responses to questions to questions about the decision-making ability of family members with cognitive impairment.

What is the likelihood that the patient...	Likely	Unlikely
...has decision-making abilities that are as good as your own?	6%	94%
...can make appropriate health decisions?	5%	95%
...would make a decision that ensured avoidance of injury?	64%	34%
...is making good decisions about day-to-day finances?	21%	79%
...is making financial decisions as well as you do?	10%	90%
...could make financial decisions (no serious mistakes or loss of money)?	38%	62%
... is making good decisions about types of food to prepare?	18%	82%
...would suffer an injury while operating a kitchen appliance?	31%	69%
... is making good decisions about managing medications?	8%	89%
...would consistently choose the correct medication/dose?	23%	77%
... would create a system to manage medications?	21%	79%

\*Percentages do not add up to 100% because answers of “Don’t Know” were excluded.

**Table 5.**

Correlation between caregiver assessment of decision-making regarding medication administration tasks and patients' overall ability to make a decision about solving a medication administration problem using the ACED instrument.

<b>Caregiver Assessment</b>	<b>Patient Decision-Making Ability n=36</b>
Likelihood the patient is making appropriate decisions about managing his/her medications	$r = 0.25, p = .14$
Likelihood the patient would choose the wrong medication or dose	$r = -0.39, p = .02^*$
Likelihood the patient would come up with a system to take his/her medications properly	$r = 0.38, p = .02^*$
Likelihood the patient would take PRN medications appropriately	$r = 0.24, p = .16$

Correlation between caregiver assessment of decision-making for financial tasks and patients' overall ability to make a decision about solving a financial problem using the ACED instrument.

<b>Caregiver Assessment</b>	<b>Patient Decision-Making Ability n=24</b>
Likelihood the patient is making appropriate decisions about day to day finances	$r = 0.39, p = .06$
Likelihood the patient is making decisions about handling his/her money as well as you	$r = 0.43, p = .04^*$
Likelihood the patient would make a financial decision resulting in a serious mistake	$r = 0.07, p = .73$

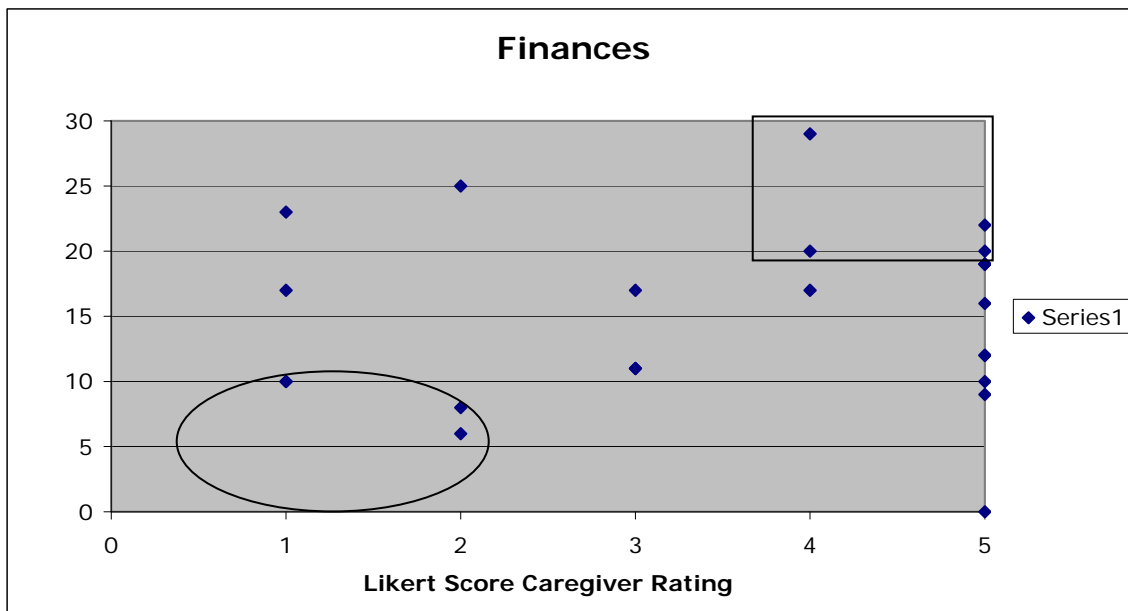
Correlation between caregiver assessment of decision-making for meal preparation tasks and patients' overall ability to make a decision about solving a meal preparation problem using the ACED instrument.

<b>Caregiver Assessment</b>	<b>Patient Decision-Making Ability n=16</b>
Likelihood the patient is making appropriate decisions about when and what type of food to prepare each day	$r = 0.48, p = .06$
Likelihood the patient would suffer an injury while operating a kitchen appliance	$r = -0.04, p = .90$

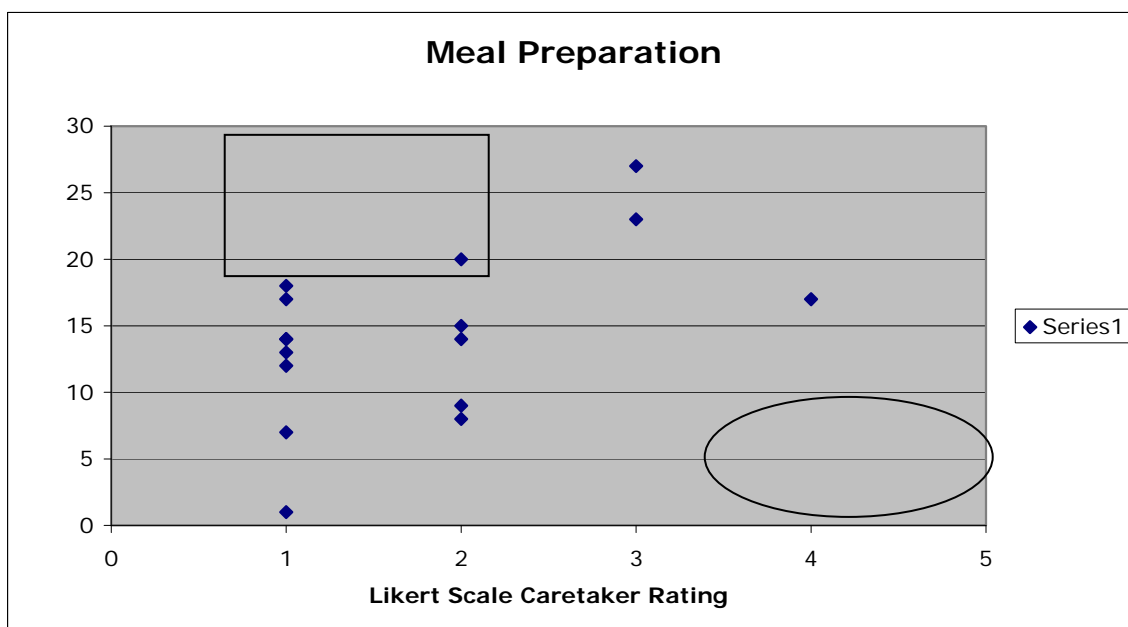
**Table 6.** Caregivers whose Likert scores of patient decision-making ability were inconsistent with ACED scores.

<b>Finances</b>			
Relationship to patient	Hours together /wk	MMSE	ACED
<i>Overestimators</i>			
Husband	168 hours	25/30	8/30
Husband	168 hours	15/30	10/30
Son of female patient	6 hours	19/30	6/30
<i>Underestimators</i>			
Husband	42 hours	22/30	20/30
Son of male patient	168 hours	28/30	29/30
Wife	40 hours	29/30	20/30
Wife	168 hours	23/30	22/30
<b>Meal Preparation</b>			
<i>Underestimators</i>			
Daughter of female patient	70 hours	25/30	20/30
<b>Medication Administration</b>			
<i>Underestimators</i>			
Daughter of female patient	30 hours	27/30	23/30
Daughter of female patient	24 hours	19/30	20/30
Daughter of female patient	17 hours	25/30	25/30
Daughter of female patient	70 hours	25/30	20/30
Wife	168 hours	23/30	23/30
<b>General</b>			
<i>Underestimators</i>			
Daughter of female	30 hours	27/30	21/30
Daughter of female	17 hours	25/30	22/30
Husband	168 hours	27/30	23/30
Son of male patient	168 hours	28/30	25.5/30
Son of female patient	12 hours	24/30	25.5/30
Wife	168 hours	23/30	25.5/30

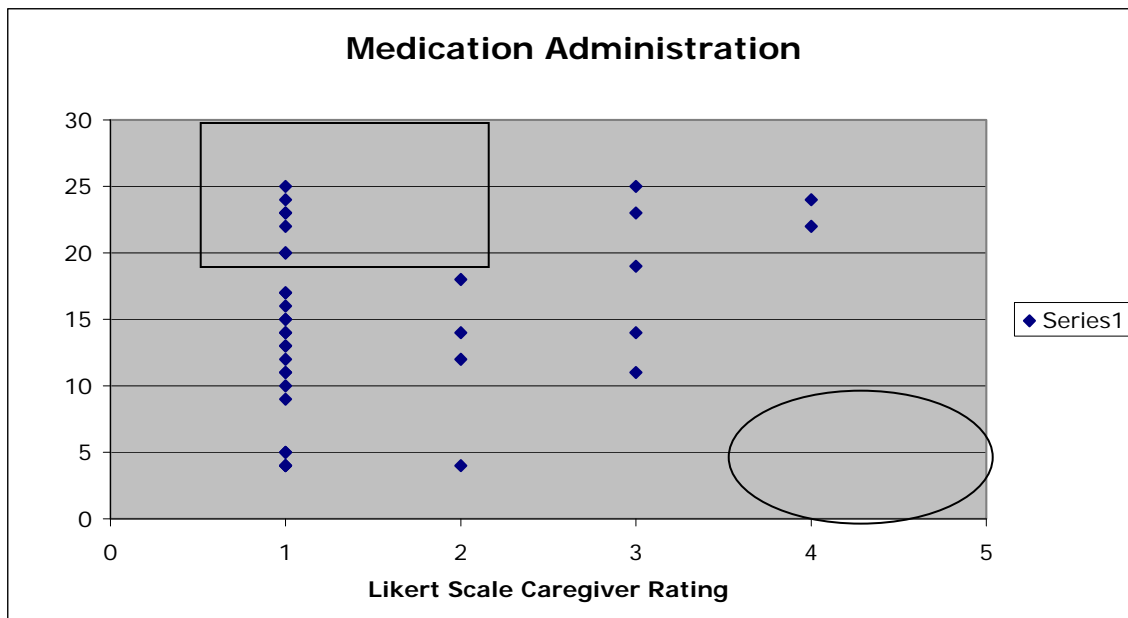
**Figure 1.** Caregiver perceptions of patient financial decision-making ability (as represented by Likert-scale score) compared with patient ACED score. A score of 5 on the Likert scale indicates poor financial decision-making. Points falling within the square represent underestimates and points falling within the circle represent overestimation.



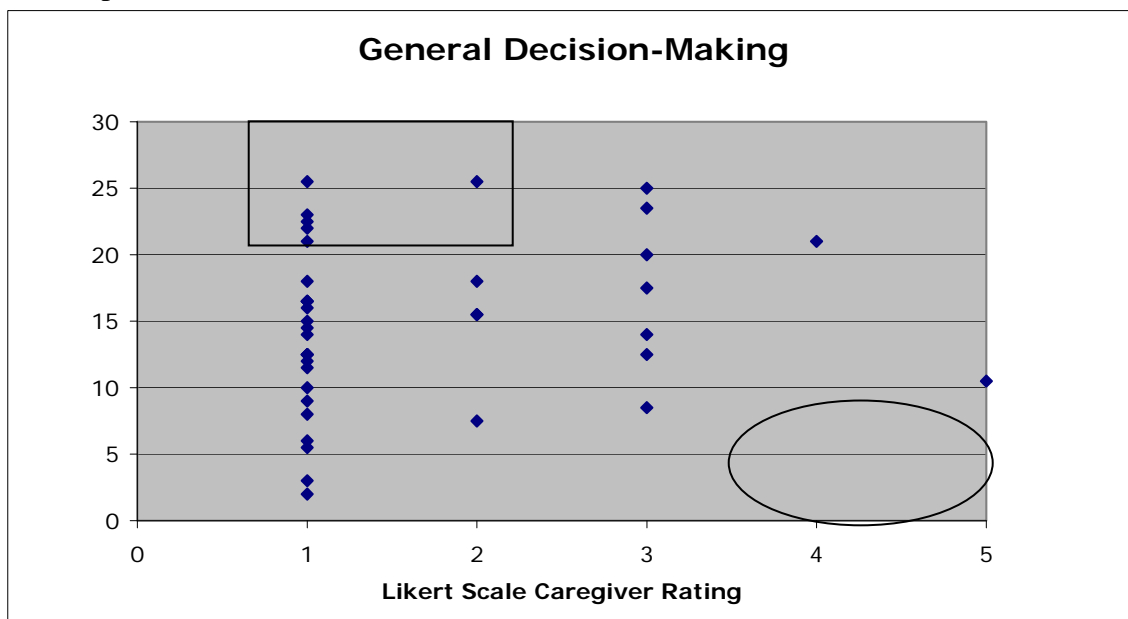
**Figure 2.** Caregiver perceptions of patient meal preparation decision-making ability (as represented by Likert-scale score) compared with patient ACED score. A score of 1 on the Likert scale indicates poor meal preparation decision-making. Points falling within the square square represent underestimates and points falling within the circle represent overestimation.



**Figure 3.** Caregiver perceptions of patient medication-taking decision-making ability (as represented by Likert-scale score) compared with patient ACED score. A score of 1 on the Likert scale indicates poor medication administration decision-making. Points falling within the square represent underestimates and points falling within the circle represent overestimation.



**Figure 4.** Caregiver perceptions of general decision-making ability (as represented by averaged Likert-scale score in two different categories) compared with patient ACED score. A score of 1 on the Likert scale indicates poor general decision-making ability. Points falling within the square represent underestimates and points falling within the circle represent overestimation.





## Discussion

This study demonstrated that there was very poor correlation between caregiver perceptions of decision-making and the scores as measured by the validated instrument, the ACED ( $r < 0.24$ ,  $p > .13$ ). Although patients were over- and underestimated as compared to ACED scores in their financial decision-making abilities, in the three other categories (meal preparation, medication administration and in general), patients were only underestimated by their caregivers, never overestimated. As shown on figures 1-4, caregivers were likely to put patients of all different decision-making abilities (as determined by ACED score) into the poorest category of decision-making. The ACED scores for patients classified by caregivers as very unlikely to make good decisions ranged from 0-22 in finances, 1-18 in meal preparation, 4-25 in medication administration and 2-25.5 overall. This variability is vast, and shows that patients who can demonstrate good ability on a standardized test were classified as incapable of making decisions by their family members. This result calls into question the validity of just using caregiver opinion to determine decision-making ability in cognitively impaired adults, as caregiver impression may not be reflective of actual decision-making capabilities or be reflecting something different than what can be captured in a test. As underestimation is more common than overestimation, patients could be having their rights abridged unnecessarily when caregiver opinion is the only source used to assess decision-making skills. With these discrepancies in mind, clearly the consistent usage of an objective instrument is needed to help clarify which patients may or may not have decision-making impairment.

Overall, caregivers indicated that there was a higher likelihood of poor decision-making in their relatives than did the ACED. All but two questions on the caregiver questionnaire yielded more than 50% negative responses about perceived decision-making ability. The two questions that resulted in a more than 50% positive response (indicating that more than 50% of caregivers felt that the patient would exhibit good decision-making) were important: both discussed avoidance of injury, one in the kitchen and one in general. Only about 1/3 of responses in both cases indicated that an injury might be incurred due to poor decision making. However, as much as 89% of caregivers indicated that patients were not likely to make correct decisions about taking medications and managing dosages. These numbers indicate that 45% of caregivers who indicated that the patient would not make a decision that would result in harm also felt that their loved one would be likely to take incorrect medications and dosages, a mistake that could certainly result in injury. This contradiction indicates that caregivers are not necessarily consistent in responses, and that their perceptions of patient decision-making and safety is informed by context: when asked specifically about medications, caregiver responses about their relatives' likely avoidance of injury were different than when the likelihood of injury question was asked generally. This difference indicates that physicians may get a different picture about patient decision-making depending upon how they ask questions to caregivers. Each interaction with each caregiver and each doctor can lead to a different picture of the patient, which leaves room for error.

Three questions posed to caregivers showed good agreement between caregiver opinion and ACED scores. Two questions were about medication (likelihood that the patient would choose the wrong medication or dose, likelihood that the patient would come up with a system to take his/her medications properly). The third question was a very general question about finances (likelihood that the patient is making decisions about handling his/her money as well as the caregiver). This data would suggest that in matters of medication administration, caregiver opinion is comparable with the objective instrument, and therefore both caregiver opinion and the ACED may closely reflect actual decision-making ability in matters of medication. The question about finances indicates that caregivers may have an accurate overall sense of the patient's financial capability, but may not be as reliable when asked about more nuanced aspects of the patient's financial decision-making.

The two questions posed to caregivers that agreed least with the ACED scores were very important questions. When opinion was compared to ACED scores, caregivers did not have an accurate sense of the likelihood of their relatives making financial mistakes or suffering an injury while operating kitchen appliances. Suffering an injury with a kitchen appliance is clearly an outcome that it is important to avoid, and if caregivers inappropriately gauge the likelihood of its occurrence, the health consequences could be significant. As for finances, caregivers were shown to both over- and underestimate financial abilities, either of which could result in far-reaching financial problems for the patient and for his or her family. Although caregivers were likely to know in general whether the patient's financial decision-making ability was better or worse than their

own, for the more subtle question regarding the likelihood of a patient making financial mistakes it was more difficult to establish caregiver reliability.

It is important to note that the context of the decision appears to strongly influence the way that caregivers describe their relatives' decision-making ability. While they were very unlikely to give under- or overestimating responses as compared to ACED score in the category of meal preparation (only one person underestimated compared to the ACED score), their ability to correctly estimate decision-making in finances was much less developed (three overestimated, four underestimated). This over- and underestimation of financial ability in cognitively-impaired patients by caregivers as compared to an objective test is consistent with previous studies (42).

Although our numbers are much too small to be able to achieve any statistically significant results, there were other trends regarding gender and the relationship to the patient that were different depending upon the category that the caregiver was being asked about (finances, meal preparation, or medication administration).

#### *The Influence of Gender*

Finance was the only category in which caregivers overestimated patients' decision-making skills as compared to the ACED. All three caregivers who overestimated the patient's abilities were male and in all three circumstances, the patient in question was female. Two of them, both husbands, spent 168 hours a week (24 hours a day, 7 days a week) with the patient. More data would be needed to confirm this trend, but these results

indicate that males may be more likely to overestimate female decision-making ability in finances, even when they are in very close contact.

Underestimators were more complicated. Fifty-nine percent of knowledgeable informants surveyed were female and of those who underestimated in relation to their ACED score, 60% were female. This would indicate that females and males are overall equally likely to underestimate their relatives' decision-making ability. Thirty-one percent of the instances of underestimation were done by males, as compared to 69% done by females. This disparity is accounted for by the fact that two of the women caregivers interviewed repeatedly underestimated in comparison to the ACED, giving low scores in two or more categories, compared to only one male who underestimated in two categories. When different sets of results representing two distinct categories were averaged and a general decision-making category was formed, the number of male and female underestimators were equal (three male caregivers, three female caregivers). Four of the patients underestimated in the general category were female and two were male, consistent with the fact that 59% of the patients studied were female.

However, within each category there were different trends. In financial decision-making, men and women were equally likely to underestimate. However, the patient who was underestimated in decision-making was more likely to be male; the ratio of underestimated males:females in finances was 3:1. This is not significant as 66% of the patients whose caregivers rated in financial decision-making were male, so male patients were overrepresented in the patient sample. However, the patient whose abilities were

overestimated in regards to finances was more likely to be female (100% of patients whose decision-making in finances was overestimated were female). These results could indicate different expectations of males versus females in financial decision-making; if men are expected to be the financial decision-makers in their families (as would be the case in many pre-1960s households), their decline in decision-making is bound to be noticed more frequently, and possibly judged more rigorously.

In the category of medication administration, all caregivers who underestimated were females; four out of five of the patients were female as well. Although the conclusions that can be drawn from this result are limited by the low number of data points, these results raise the question of whether women are more likely to harshly judge in medication-related questions.

### *The Impact of Relationship*

Beyond the issue of gender, certain relationships between patient and caregiver can also alter perceptions of decision-making ability. Daughters and wives, sons and husbands – the dynamics in these relationships are certainly different. Daughters were the most likely to underestimate, representing 40% of underestimators; sons, husband and wives each represented 20%. All of the daughters underestimated their mothers, but it must be noted that there were no daughters of male patients interviewed in this study. In this study, all but one caregiver were interviewed about medication administration. Four of the eleven daughters interviewed about medications underestimated as compared to the ACED scores (36%). None of the sons or husbands interviewed under- or overestimated

as compared to the ACED in this category. Only one of the eleven wives interviewed about patient medication decision-making underestimated her spouse.

#### *The Role of Hours Spent with the Patient*

The difference between the number of hours invested per week by caregivers who gave congruent versus incongruent estimates of patient decision-making was minimal.

Husbands and wives spent more time with the patient than did daughters and sons. The lack of significance indicates that number of hours spent with the patient should not necessarily be privileged when considering a caregiver's prediction of decision-making.

It could be argued that time spent with the patient may serve as a proxy for the amount of burden the patient represents. If this were true, then one would have to conclude that burden in this case did not influence a caregiver's perception of the patient's decision-making ability. However, time spent with the patient may not in fact represent burden. As this study did not directly assess burden, no further conclusions can be drawn regarding this topic.

#### *MMSE Scores and Perception of Patient Decision-Making*

There was an unexpected result regarding MMSE scores and caregiver accuracy in assessing decision-making. In previous studies, it has been shown that patients with high MMSE scores would be more likely to be overestimated in their ability to perform ADLs. In this study, however, patients who were underestimated had significantly higher MMSE scores. Their average was 25, as compared with 20 for those who were overestimated and

21 or those whose estimate was congruent with the ACED score. In short, overestimated patients had the lowest MMSE scores and underestimated patients had the highest. The difference between the overestimated patients' MMSE scores and accurately-assessed patients was statistically significant ( $p=0.01$ ), as was the difference between overestimated and underestimated patients' MMSE scores ( $p=0.04$ ). ACED scores resembled MMSE scores for the underestimated group. Mean ACED score was 23/30 as compared to the mean MMSE, which was 25/30. The reason for this disparity between MMSE score and caregiver assessment is unclear.

#### *Areas of Weakness*

There were some adjustments that could be made to this study in future studies that may yield enlightening results. Caregiver burden is a very important concept, and may influence the way that caregivers assess decision-making, as it has been shown to influence other aspects of caregiver perception of cognitively-impaired patients such as physical ability, ability to perform ADLs, competency and patient quality of life. In this study, we did not focus on caregiver burden. In future studies, caregiver burden should be assessed using an established caregiver burden scale. Caregiver depression would also be an important parameter to assess, as it can change perceptions of patients and can also be associated with burden. In this study, burden was not reflected by time spent with the patient, but this parameter could also be used to understand burden in future studies.

Most of the patients included in this study were Caucasian. As such, no assessment regarding the race or ethnicity of patients and caregivers and the way these variables alter



perception of decision-making ability could be made, and this study is not generalizable to all races. Race has been shown to effect the way that caregivers perceive quality of life and ability in previous studies, and it is reasonable to suspect that it may play a role in the caregiver's understanding of decision-making ability as well.

Additionally, the ACED, though validated against other measures of cognitive function that effect decisional capacity, is a very new instrument and will no doubt undergo a series of tests to further assess and hone its use as an accurate measurement of decision-making. Further studies could be conducted to examine ACED scores as compared to actual witnessed patient performance at home or in a simulated environment when performing tasks that require decision-making. Caregiver perceptions could also be compared to conclusions drawn by physicians regarding decision-making after watching several in-home or simulated task sessions such as meal preparation or medication administration. Good inter-scorer reliability has been demonstrated in the validation of the ACED (25), but the influence of other environmental (e.g. survey performed at home vs. at a clinic) or situational factors could also be examined. Additional, more formal cut-offs should be examined to define good performance vs. poor performance on the ACED. For the purposes of this study, 10/30 was defined as poor performance and 20/30 was defined as good performance. These cut-offs were selected on the basis of the experiences of the author and Dr. James Lai. More studies will be needed to verify whether these cut-offs are actually meaningful.

The sub-analysis of factors that correlate with underestimation or overestimation included too few patients to be statistically analyzed. The result indicating that MMSE score is likely to be higher in underestimated patients is unusual, and inconsistent with previous studies. It would be interesting to see if these results are reproducible, or whether they represent an anomaly in this study. As only 39 patients were included in this study, a larger study would certainly be beneficial and could assist further understanding of other trends, such as the degree to which gender and relationship influence caregiver perception of patient decision-making in cognitively impaired patients. In this study, there were only thirteen caregivers whose perceptions of patient decision-making ability were not consistent with patient ACED scores, and therefore it was difficult to draw conclusions with complete confidence.

Although instruments can take more time to administer, this study indicates that the use of an objective system of measuring decision-making ability gives information that differs from caregiver perceptions. It is difficult to say why daughters may be more likely to inaccurately assert that their mothers take medications improperly, or why males may be more likely to overestimate the financial capacities of their female relatives. However, it is likely that caregiver perception and objective measurement each lend a unique perspective that may ultimately be useful in more accurately determining decision-making ability.

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