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Assessing the Capacity to Make Everyday Decisions: A Guide for Clinicians and an Agenda for Future Research

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Abstract
Assessing the capacity of patients to make decisions about their functional problems has substantial ethical, clinical, and financial implications. The growing population of older adults with cognitive impairment either in the community or in long-term care and medical facilities increase the importance of adequately assessing this capacity. This review examines the current approaches to making this assessment, demonstrates how they are incomplete, and considers potential approaches for improving these evaluations. Future research should develop and validate methods to identify patients with impaired capacity to make everyday decisions. These data will supplement functional, cognitive, and medical assessments.

Keywords
capacity, cognitive impairment, decision-making, dementia, activities of daily living

Comments
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Assessing the Capacity to Make Everyday Decisions: A Guide for Clinicians and an Agenda for Future Research

James M. Lai, M.D., Jason Karlawish, M.D.

An 84-year-old woman hospitalized for treatment of pneumonia is ready for discharge alone to her home. Over the past week, her daughter has discovered mispaid bills and two full bottles of her mother's medications. The patient has a Folstein Mini-Mental Status Examination of 28. The daughter and discharge planner wonder if it is safe for this patient to return home.

Competency assessments are a common and necessary part of caring for older patients with cognitive impairment. They help in measuring the clinical impact of cognitive deficits,[1–6] in choosing the types of resources a patient needs,[7–9] and in determining whether and how to limit a patient's independence.[10–12] Clinicians, however, face considerable challenges in accurately and reliably identifying impaired competency, because the assessments are complex and require the evaluation of at least two components: the capacity to perform a task and the capacity to make a decision.[13] Thus, for example, patients such as the one described in the case here may lack the ability to perform their basic or instrumental activities of daily living—collectively referred to as ADLs—but still retain the capacity to make decisions about when and why they need to perform them.

At present, clinicians and clinical investigators have several validated and clinically applicable

methods to assess functional tasks.[14,15] They, unfortunately, do not have equally valid or clinically applicable methods to assess a patient's capacity to make everyday decisions. Specifically, they do not have instruments able to assess if a patient is capable of solving problems in performing his or her ADLs.

The absence of such decision-making assessment tools has implications on the care of patients with cognitive impairment. Patients incorrectly judged unable to solve problems in performing their ADLs will lose at least some of their autonomy because a surrogate makes decisions about these ADLs. In addition, clinicians may require these patients to receive additional caregivers in the home or even move into a long-term care facility. The failure to adequately assess a patient's capacity to make decisions about how to manage ADL problems may also affect how closely clinicians follow-up patients with mild cognitive impairment (MCI).[16,17] This has important clinical implications, because impairments in decisional ability, in particular the ability to appreciate ADL impairments, may represent a greater risk for progression of MCI to dementia[18,19] and may unknowingly expose patients to adverse events in performing their ADLs, financial abuse, or self-neglect. Lastly, for residents in long-term care and skilled nursing facilities, assessments of decision-making capacity are a proxy for the degree of care residents require and are a factor in determining how much financial reimbursement the facility receives.[20] Thus, errors in assessing decision-making capacity affect not only the quality of resident care, but also may lead to miscalculations in the costs of healthcare delivery. Moreover, as the numbers of elderly persons with cognitive impairment are projected to increase, these problems will only increase.[21]

Clearly, an instrument that allows clinicians to reliably assess the capacity of persons to make decisions about how manage their own functional problems will substantially influence the treatment of patients with cognitive impairment. If clinicians can accurately distinguish patients who are capable of making their own choices about their care from those who cannot, families, case managers, and discharge planners can allocate healthcare resources, supervision, and assistance more effectively to the patients who most need these services. In long-term care settings, this kind of instrument will help more accurately predict the costs of staffing and resources needed to care for residents. Finally, measuring a patient's capacity to make everyday decisions provides a real-world outcome that clinical investigators can use to predict the progression of cognitive decline and to assess the response to potential cognitive-enhancing therapies.

Unfortunately, our current approaches to assessing this capacity are limited. In this clinical review, we set out to describe the types of patients who would be expected to benefit from assessments of everyday decision-making capacity, demonstrate how the current approaches are inadequate, and then outline potential directions for the development of new methods to fill this gap.

HOW PATIENTS BENEFIT FROM CAPACITY ASSESSMENTS IN EVERYDAY DECISION-MAKING

Assessing a patient's capacity to solve his or her own functional problems has the potential to improve clinical outcomes for: 1) patients who must perform their own ADLs to live independently; 2) patients whose decision-making capacity determines how much assistance they receive such as those in long-term care facilities; 3) patients who receive cognitive-enhancing therapies with the goal of increasing their level of independence; and 4) patients with cognitive impairment who do not have dementia.

Patients With Cognitive Impairment Who Live Independently

Cognitive impairments, especially those caused by Alzheimer disease,[21] are a common and increasing cause of disability among community-dwelling elderly.[22,23] When these patients experience deficits in their ADLs, clinicians must decide whether to limit their independence. The interventions clinicians recommend to protect patients from harms that may occur as result of their ADL deficits must serve the best interests of the patient and also respect patient autonomy.

The way to do this is to assess a patient's capacity to make decisions about how to manage his or her ADL problems. Patients with impairments in capacity are at risk for harms such as financial abuse,

medication misuse, unsafe driving, and poor nutrition. Thus, the more accurately a clinician assesses patients' capacity to make everyday decisions, the better the clinician is able to gauge the level of assistance patients need to maintain their safety while at the same time preserving their independence.

A challenging instance of making this assessment is when discharge planners, case managers, and clinicians in hospitals, skilled nursing facilities, and emergency departments must decide whether a patient with functional impairments is capable of making decisions about how to solve these impairments.[24–26] Patients lacking this capacity may require greater assistance in the home or should be supervised until either a safer living arrangement is available or they demonstrate the ability to live safely. The failure to consider decision-making ability in discharge planning may be a factor contributing to high rates of emergency services use[27] and adverse outcomes after emergency department discharge in this population.

Patients Requiring Assistance in Institutionalized Settings

At least half of residents in long-term care facilities have some form of cognitive impairment.[28,29] Personnel are responsible for identifying residents who are able to make decisions about their care from those who cannot. Ideally, personnel then provide residents with the assistance that maximizes their independence while at the same time protects them from the harms caused by the choices they cannot make. Federal nursing home regulations mandate that nursing home and skilled nursing facilities use a resident assessment instrument (RAI) to document residents' everyday decision-making performance.[30] This documentation monitors the quality of care and creates nursing care plans for each resident.

The primary RAI instrument to assess everyday decision-making is the Minimum Data Set (MDS) 2.0.[31] It involves clinical observation, informant report, chart review, and the use of available cognitive data. As valuable as these data are to inform a capacity assessment, what is missing is a direct measure of capacity. This gap means that the quality of decision-making evaluations may vary widely within and between institutions. Thus, patients with impaired decision-making abilities may receive too little assistance, whereas others, capable of making decisions, may be deprived of opportunities to make choices about their own self-care.

This gap also has financial implications. Medicare calculates the prospective payments paid to participating skilled nursing facilities using the results of the MDS measure.[31] These payments can best be calculated if the assessment precisely measures the decision-making abilities of patients in managing the specific functional problems that occur within the institutionalized care setting. Furthermore, institutions may also more effectively distinguish their case mix of patients and the overall burden of care they carry with the goal of more accurately estimating the level of reimbursement they should receive for their services.

Patients Who Are Candidates for Cognitive-Enhancing Therapies

The ability of cognitively impaired patients to make decisions, in particular, decisions about how to manage their own functional problems is an outcome measure that has the potential to demonstrate the clinical effectiveness of cognitive-enhancing therapies. Therapies shown to enhance or retard declines in decision-making ability provide clinicians with information about how that therapy might influence their patients' independence. Furthermore, therapies shown to improve decision-making ability may change clinical management in patients with very mild to moderate-stage dementia in which there is a known variability in decision-making ability.[32] Thus, measuring decision-making ability as an outcome may show that a cognitive-enhancing therapy has in fact enhanced cognition in a clinically meaningful manner.

Patients With Cognitive Impairment Who Do Not Have Dementia

A fourth group of patients that may benefit from methods designed to identify impairments in the capacity to make everyday decisions are patients with MCI[1] and cognitive impairment no dementia.[33] These patients lack the degree of functional and cognitive impairments necessary to make a diagnosis of dementia. However, some persons with MCI do have deficits in instrumental ADLs.[17,19,34–36]

Limited studies of decision-making capacity in

persons with MCI suggest that those who are unaware of their functional deficits are more likely over time to develop dementia.[19] This suggests that measuring these patients' capacity to solve these instrumental ADL problems can reveal important information about the clinical and prognostic significance of their functional deficits or signal the need for earlier treatment such as with therapies shown to improve decision-making ability.[37,38]

PROBLEMS WITH THE CURRENT APPROACH TO ASSESSING EVERYDAY DECISION-MAKING

At present, three techniques exist to inform clinicians about a patient's ability to make decisions in solving his or her functional problems. Unfortunately, none of these are well accepted and none are specifically designed to determine whether a patient is capable of making decisions about how to solve his or her own ADL problems.

Existing Decision-Making Assessments

Most capacity assessment instruments focus on helping clinicians determine whether a patient has the capacity to make a medical treatment or research decision.[39–41] Only one instrument, the Decision-making Instrument for Guardianship (DIG),[42] evaluates the capacity to make decisions about problems encountered in everyday living. However, the DIG is not a clinically applicable instrument. It was primarily developed to assist the courts in guardianship assessments and in evaluating whether a person has the capacity to make decisions about *potential*, not actual, problems encountered in everyday living. Hence, although the DIG is comprehensive (it addresses capacity across eight hypothetical problems such as hygiene and money management in property acquisition), its use of hypothetical scenarios presents two shortcomings.

First, use of a hypothetical scenario as the basis for a decision-making evaluation may potentially complicate the interpretation of subsequent responses to questions that require the patient to grasp this abstract, initial premise. This is not to say that other existing capacity assessments do not evaluate patients in their ability to abstract. On the contrary, an important aspect of assessing a person's reasoning is to consider a person's ability to generate potential consequences surrounding an option. However, in cases where patients fail to appreciate that they are being asked to consider how they would act in a situation that does not necessarily exist, the DIG may result in an assessment that does not truly reflect their actual decision-making ability. Second, the clinical value of data yielded from a patient's responses to a hypothetical exercise diminishes as the circumstances of the hypothetical situation deviate from the patient's actual problem. Clinicians need an instrument that allows them to assess the capacity to make a decision that is related, as closely as possible, to their patient's social, environmental, and medical situations.

Second, the DIG cannot assess a patient's capacity to appreciate his or her functional problems. Although the DIG assesses other important aspects of decision-making capacity, the failure to evaluate whether patients are able to recognize how a problem and its potential solutions pertain to their situation omits valuable information because this finding may help clinicians discern whether these patients are capable of implementing a proposed solution[32] and may serve as an useful maker for future cognitive decline.[19]

Patient Judgment Assessments

Instruments that assist clinicians in characterizing a patient's judgment evaluate patients on their responses to a problem scenario. Responses that deviate from accepted norms established by a group of cognitively intact older patients indicate impaired judgment. Although these data represent a component of capacity, they alone are not an assessment of a patient's decision-making capacity. Specifically, they do not describe the patients' abilities to understand, appreciate, reason, and express a choice about how they would solve their functional problems.

Additionally, the failure to consider decisions the patient actually faces further limits the value of judgment assessments. As with the DIG, instruments that use hypothetical scenarios yield data that can be difficult to interpret in a clinical context. For example, it is unclear what poor performance in answering the question, "You notice your dog is limping. What would you do?" on the Problems in Everyday

Living Test[43] reflects about the patient's capacity to make other decisions that may more directly affect the ability to live independently. Other instruments such as the Everyday Problems Test for Cognitively Challenged Elderly[44] and the Everyday Problems Test[45] designed to assess a patients' ability to solve hypothetical tasks related to higher-order instrumental activities of daily life also measure judgment in a similar manner. Although these tests may still have value in characterizing the cognitive abilities of the patient, the measurement is less useful as a way of accurately identifying patients with impaired decision-making.

Alternatively, an instrument such as the Financial Capacity Instrument (FCI),[46] which assesses financial judgment as part of a task-based evaluation of financial ability, is more clinically applicable. The FCI tests financial knowledge, the ability to perform financial activities, and judgment in performing relevant monetary transactions. Although this more closely and comprehensively recreates the types of decisions and abilities that patients might actually face and provides information about a patient's capacity to make financial decisions, it lacks the portability found in formal decision-making instruments and is limited to evaluating one, albeit important, functional activity.

Proxy Assessments of Patient Decision-Making

Clinicians may gauge a patient's capacity to make everyday decisions by asking a knowledgeable informant such as a partner or adult child. Compared with other approaches, clinicians likely use this approach most frequently. Although it provides valuable historical data, the disadvantage is that an informant's assessment tends to have reduced reliability and consistency.[47] Many factors, including the amount of time spent with the patient or conflicts of interest, may influence the informant's assessments. These evaluations provide useful information in gaining an overall impression of the patient's abilities, but they do not provide the type of structured and detailed assessment clinicians need to make treatment decisions about when and how to limit a patient's independence.

A NEW APPROACH TO ASSESSING EVERYDAY DECISION-MAKING CAPACITY

The challenge for researchers is to develop clinically applicable tools that allow clinicians to quickly and reliably evaluate patients' abilities to make decisions about how to solve their own problems. One potential approach to assessing everyday decision-making builds on previous research in assessment tools designed for evaluating the capacity to make medical decisions.[39,41] For these types of decisions, decision-making ability is measured in four areas that have been previously identified through review of the standards used by expert clinicians and the court system in legal competency evaluations: understanding, appreciation, reasoning, and choice.[48] Table 1 defines these decision-making abilities and outlines their key clinical characteristics. Semistructured interviews such as those used with the MacCAT-T[39] that measure these abilities provide clinicians with a quantitative evaluation of the patient's decision-making capacity for medical decisions.

Table 2 outlines an analogous approach. It provides the template for a semistructured interview that could be used to evaluate a person's ability to make an everyday decision. In this example, the clinician presents the patient with a known functional problem such as difficulty in managing his or her checkbook. The clinician then asks the patient a series of questions to determine whether he or she understands this problem and whether he or she appreciates this as being *his or her* problem. Next, the clinician provides a set of possible solutions that includes an explanation of the benefits and risks to these solutions. To evaluate reasoning ability, the clinician asks the patient to consider these choices and compare a choice the patient desires with other possible choices. The patient is also asked to describe the everyday consequences that he or she feels would likely occur if one or more of these choices were enacted. The ability to express a choice and the logical consistency of this choice would be determined by asking the patient to select one final solution at the completion of the interview and then to explain the rationale for that choice.

There are at least three reasons why this type of semistructured interview assessment may improve

TABLE 1. Definitions of the Four Decision-Making Abilities and the Clinical Characteristics of These Abilities in the Setting of Older Patients With Dementia

Ability	Definition	Clinical Characteristics
Understanding	The ability to comprehend basic information about a problem, its potential solutions, and the risks and benefits associated with those solutions	This ability is often highly impaired in the setting of mild to moderate-stage dementia[41] May be influenced by level of education and intelligence and how information is presented
Appreciation	The ability of a person to recognize how a problem or solution pertains to his or her specific situation	Impairments manifest as a loss of insight or behaviors of denial in the clinical setting Depending on the type and complexity of the decision, the range of impairment may vary considerably among patients with mild to moderate-stage dementia[52,52,53]
Reasoning	The ability to consider potential solutions to problems by: 1. Demonstrating how one solution is better in comparison to another 2. Describing how a solution would affect his or her everyday life 3. Demonstrating a logical thought process in determining a choice	This ability is frequently impaired in mild and especially in moderate stages of dementia[52,54] Performance in this ability may decline rapidly along with the progression of cognitive decline[52]
Expressing a choice	The ability to render a clear choice for the decision under consideration	Impairment is often preserved despite the presence of impairments in other decisional abilities and, when present, is associated with more advanced stages of dementia[52,53–55]

on existing methods. First, it offers clinicians the opportunity to evaluate decision-making abilities with respect to an actual decision the patient currently faces. This provides a degree of face validity that is particularly valuable in persuading caregivers or family members to act as a surrogate decision-maker for their loved one. Second, with training, clinicians may participate in the collection of these data in nursing homes, hospitals, and outpatient clinics where it has the greatest potential of influencing patient care. Third, research has previously demonstrated that use of decision-making instruments using this framework may significantly improve clinicians' ability to distinguish patients with impaired decision-making over their clinical judgment alone.[49]

Significant methodological hurdles, however, do exist in the development of a capacity assessment instrument that can be adapted to handle patient specific everyday decisions. For example, the use of caregiver-derived information in the assessments and the subjective scoring of patient responses may impact the overall reliability and test–retest characteristics of the instrument. Thus, before being used with the purpose of tracking changes in decisional ability over time, instruments with this type of flexible template may require modifications or restrictions in its administration or perhaps alterations to the instrument itself. In addition, with the increased adaptability of the instrument comes increased complexity, and clinicians in the field may require additional supplementary training to achieve the same level of psychometric performance as could be demonstrated in a research setting. Together, these limitations suggest that standardized, vignette-based approaches to capacity assessment may also be needed to complement any flexible template approaches. Future research comparing the relative value of these two methods will be needed to clarify these important issues.

A PROPOSED MODEL FOR THE ASSESSMENT OF EVERYDAY DECISION-MAKING CAPACITY

The purpose of assessing a person's capacity to make everyday decisions is to help provide patients with the necessary decision-making assistance where they need it while preserving their autonomy for other

TABLE 2. Template of an Interview Designed to Assess the Capacity of the Patient Described in the Initial Case to Make the Decision About How to Manage Her Medications[a]

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 *not* 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?"

[a]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.

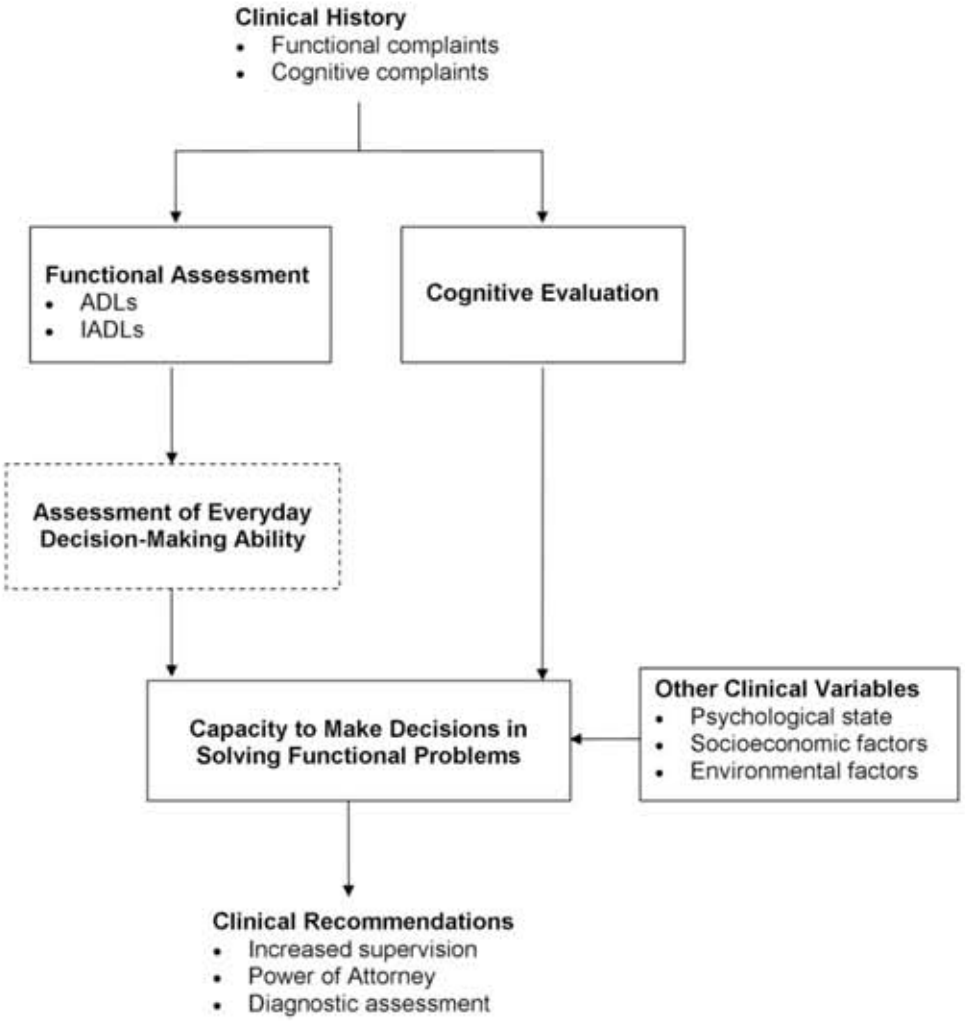
decisions where their capacity is not impaired. Data from these assessments do not alone determine how and where patients should live and what assistance they require. However, approaches such as the one described in Table 2 do provide a way to help determine whether a patient's decision is in fact a competent choice. As with capacity assessments for other types of decisions, evaluation of a patient's ability to make decisions about how to solve one's own functional problems provides only one component, albeit

an important component, of a multistep assessment that incorporates knowledge of the patient's functional, psychological, socioeconomic, and medical state. Figure 1 shows a conceptual model for how clinicians may integrate these types of capacity assessments into their clinical algorithm when trying to make recommendations about needs for assistance, supervision, and surrogate decision-making.

To illustrate the complexity involved with performing and interpreting capacity assessment data in the context of other clinical factors, consider the case of the 84-year-old woman described in the introduction. A key clinical question in deciding whether to allow this woman to return home is: does the evidence of impaired functional behavior represent manifestations of delirium that began before she was admitted, a loss of physical function (e.g., impaired eyesight), an overall decline in her capacity to make decisions related to progressive cognitive deficits, or is this behavior consistent with previous "normal" behavior of noncompliance? In reality, the etiology is likely the result of a combination of factors.

Given the limited assistance this patient would

FIGURE 1. Model for Assessing the Capacity to Make Decisions About How to Solve Functional Problems



ADL: activities of daily living; IADL: instrumental activities of daily living.

receive after returning home, an appropriate predischarge assessment would begin with functional testing by an occupational therapist and with obtaining further history from family members on the patient's prior level of functioning. At a minimum, in addition to the Mini-Mental State Examination, a brief evaluation of executive function using an instrument such as the EXIT examination[50] would give a broader measure of her cognitive deficits. A delirium assessment and screen for depression would also be essential in appropriately documenting her psychological state.

In the absence of an acute medical process or chronic physical impairment that adequately explains her functional loss, one would then ideally want to then characterize her ability to make decisions about how to solve her functional problems and then document her decisional skills within the context of the common language of the decisional abilities described in Table 1. Clearly, the absence of a rigorously tested and well-established instrument designed to assist in collecting this kind of data limits the degree to which clinicians may apply these observations in the actual management of patients. Future research will be needed to ultimately determine the clinical value of such an assessment. Nonetheless, in the meantime, an approach similar to that which is described in Table 2 may offer clinicians, at the very least, useful information that may augment our existing and insufficient everyday decision-making assessments.

CONCLUSIONS

Assessing whether patients themselves are able to decide how much assistance they require in their current living situation has ethical, clinical, and financial costs. The growing population of older adults with cognitive impairment as well as a higher propensity for these same persons to be living in isolation either within the community or within the confines of a medical facility will only increase these costs. Current approaches to assessing patients' capacities to make decisions about their own functional problems are limited. Future research should involve designing, validating, and implementing practical clinical tools aimed at directly assessing the capacity of patients to make decisions about how to solve their own problems. These methods should apply the language and framework developed for the assessment of medical decision-making capacity, thus creating a common vocabulary for describing patients with an impaired capacity that can improve both the consistency and accuracy of these assessments.[51]

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