



## Empirical advances in the assessment of the capacity to consent to medical treatment: Clinical implications and research needs

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### Abstract

The clinical evaluation of capacity to consent to treatment occurs in the medical setting and is based on legal foundations of informed consent and capacity. Clinical judgment is still the “gold standard” for capacity determination, although it can be unreliable. In the past 10 years the empirical basis for these assessments has been advanced considerably by the introduction of a number of instruments designed to assess capacity to consent to treatment. In this paper, we review studies, mostly with older adult populations, that consider the cognitive and non-cognitive correlates of consent capacity, rates of impaired capacity in various patient groups, the relation of instrument-based to clinician-based capacity assessment, and the inter-rater and test–retest reliability of consent capacity assessment. We also overview key research focusing on factors influencing, and procedural and processing variables involved in, medical decision-making. We conclude that these studies have yielded quite varied results, and promote no consensus regarding the reliability and validity of instrument-based consent capacity assessment. Overall, the results of these studies provide some guidance for clinicians, but, at present, practitioners should view these instruments as supplemental resources rather than benchmarks for assessment. However, this first generation of instruments provides a good foundation for future research, which should

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continue to systematically study aspects of reliability and validity, most especially construct validity, in well-defined patient populations.

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## **1. Introduction**

This paper describes the empirical findings concerning capacity to consent to treatment or “consent capacity” with a focus on the utility and limits of instruments designed to assess consent capacity, so-called “forensic assessment instruments” (Grisso, 2003). We also relate capacity assessment to the more general literature on medical decision-making. We will focus mostly but not exclusively on the assessment of older adults, as most studies are based on this population. Our goal is to provide a synthesis of consent capacity research, with recommendations for researchers and clinicians, although clinicians seeking specific instruction in capacity assessment procedures and tools should refer to more applied resources in this area (e.g., Moye, 1999).

### *1.1. Key concepts*

We will use the term “capacity” to refer to a dichotomous (yes/no) judgment as to whether an individual has the abilities to make a treatment decision. In the health care setting, questions of consent capacity rarely proceed to adjudication, unless extraordinary treatment is involved or guardianship is being pursued. In this paper, we will refer to judicial determinations of consent capacity as “competency.” The term “decisional abilities” will be used to describe the functional elements of consent capacity as articulated by Grisso and Appelbaum (1998), specifically: understanding, appreciation, reasoning, and expressing a choice, described below.

### *1.2. Current clinical practice*

Informed consent for medical treatment requires disclosure (providing information), voluntariness (lack of coercion), and capacity (Eth & Leong, 1992). If the clinician doubts a patient’s capacity to make a medical decision, a formal evaluation of capacity by an expert clinician is likely to ensue. A clinician’s opinion is the current “gold standard” for capacity determination and is typically based upon clinical interview, medical record review, and mental status examination (Marson, Ingram, Cody, & Harrell, 1995; Nash & Giles, 1989). Federal psychological practice guidelines recommend use of a clinical interview, standardized neuropsychological tests, and forensic assessment instruments (Department of Veterans Affairs, 1997). Unfortunately, actual practice falls far short of this ideal. For example, in a nursing home study, the primary factor in determining a resident’s capacity to write an advanced directive was orientation to person, place and time as evaluated by the social worker, nurse, or clerical staff (Walker, Bradley, Blechner, & Gruman, 1996). A national survey of 395 clinical practitioners found continuing confusion regarding the assessment of capacity (Ganzini, Volicer, Nelson, & Derse, 2003). Common pitfalls included confusion between clinical assessments of capacity and legal determinations of competency, the belief that actions against

medical advice indicate incapacity, and the assumption that cognitive or psychiatric disorders necessarily imply incapacity.

### 1.3. *Legal standards for practice*

While clinical assessments of consent capacity are not the same as judicial determinations of competency, legal definitions of incapacity inform clinical practice; clinical evaluations should be consistent with the law. In the United States, most statutory definitions of incapacity for civil matters (i.e. those that may necessitate a guardian or other substitute decision maker) include four requisite elements: 1) a disease or disorder, that causes; 2) cognitive or psychiatric impairment, that leads to; 3) functional (meaning behavioral or decisional) disabilities on a specific task or decision, that exceeds; 4) an acceptable risk threshold to the person or society as weighed by an expert clinician or judge (Anderer, 1990; Sabatino & Basinger, 2000). A widely accepted taxonomy of the functional abilities needed for consent capacity is: Understanding, Appreciation, Reasoning, and Expression of choice. These functional abilities, which have been described in a series of reviews of case law and medical ethics, comprise the current legal standards for consent capacity (Appelbaum & Grisso, 1988; Drane, 1985; Roth, Meisel, & Lidz, 1997; Tepper & Elwork, 1984).

*Understanding* is the ability to comprehend diagnostic and treatment-related information. It includes the ability to remember and comprehend newly presented words and phrases, and to demonstrate that comprehension by paraphrasing diagnostic and treatment information. *Appreciation* refers to the ability to relate the treatment information to one's own situation, in particular, the nature of the diagnosis and the possibility that treatment would be beneficial. Thus, understanding emphasizes comprehension while appreciation focuses on personal relevance and beliefs. Disavowal of the diagnosis or potential treatment benefit may signify a deficit in reality-testing (e.g., delusional disorder) or neurologic dysfunction (e.g., anosognosia), but may also reflect culturally or experientially based beliefs (which is not a basis for incapacity) (Appelbaum & Grisso, 1992). *Reasoning* is the ability to evaluate treatment alternatives by integrating, analyzing, and processing information in order to compare them in light of potential consequences and their likely impact on everyday life. Reasoning has been operationalized as the ability to state rational explanations, to process information in a logically consistent manner, or to manipulate information rationally. *Expressing a choice* is the ability to communicate a decision about treatment.

### 1.4. *Instruments for the evaluation of consent capacity*

A major empirical advance in the past 10 years has been the development of assessment instruments and interview guides for evaluating capacity to consent to medical treatment. These instruments are meant to aid clinical evaluation; however, a score on such an instrument is never meant to supplant clinical judgment. Returning to the statutory model previously presented, capacity instruments are used to assess item three, functional abilities. The assessment of functional abilities is considered in conjunction with information about the diagnosis, cognitive abilities, and risk of harm. Clinical judgment is the process of weighing all these sources of data in light of the dual ethical obligations to promote autonomy and to protect the individual from harm.

In this review, we describe research based on these consent instruments. First, a brief summary of each instrument is included describing the domains measured, method, vignette content (if a

hypothetical vignette is used), and reliability data (if available). Example items are provided where such examples may clarify measurement approaches. The summary of the instruments is meant to provide a basis for the subsequent research review; more detailed information is provided in the primary reference and, for most instruments, also in Grisso (2003). Of note, we do not review studies focusing on evaluation of capacity to complete an advance directive, which is a separate decisional task (e.g., studies using the Hopkins Capacity Assessment Test (HCAT); Janofsky, McCarthy, & Folstein, 1992).

#### 1.4.1. *Aid to capacity evaluation (ACE) (Etchells et al., 1999)*

The ACE is a semi-structured assessment interview that addresses seven facets of capacity for an actual medical decision (not a standardized vignette): the ability to understand (1) the medical problem, (2) the treatment, (3) the alternatives to treatment, and (4) the option of refusing treatment; the ability to perceive consequences of (5) accepting treatment and (6) refusing treatment; and (7) the ability to make a decision not substantially based on hallucinations, delusions, or depression. These reflect legal standards in Ontario, Canada, but also correspond to U.S. legal standards. Questions in the first four areas assess the decisional ability of understanding. Questions in areas five and six appear to tap reasoning, and in area seven diminished appreciation based on patently false beliefs (e.g., “Do you think we are trying to harm you?”). The ACE includes scoring guidelines and rates patients as definitely incapable, probably incapable, probably capable, or definitely capable.

#### 1.4.2. *Capacity assessment tool (CAT) (Carney, Neugroschl, Morrison, Marin, & Siu, 2001)*

The CAT proposes to evaluate capacity based on six abilities: communication, understanding choices, comprehension of risks and benefits, insight, decision/choice process, and judgment. It uses a structured interview format to assess capacity to choose between two options in an actual treatment situation; as such, it does not use a hypothetical vignette. In a pilot study, examiners presented the patient with two options (e.g., go to a nursing home or go home with assistance). The patient’s registration, recall, description of the choices, descriptions of risks and benefits of those options, “insight” (not defined), ability to explain reasons for a choice, and ability to discuss how to handle a potential problem associated with a choice (e.g., falling at home) were rated.

#### 1.4.3. *Capacity to consent to treatment instrument (CCTI) (Marson, Ingram et al., 1995)*

The CCTI is based on two clinical vignettes; a neoplasm condition and a cardiac condition. Information about each condition and related treatment alternatives is presented at a fifth to sixth grade reading level with low syntactic complexity. Vignettes are presented orally and in writing; participants are then presented questions to assess their decisional abilities in terms of understanding, appreciation, reasoning, and expression of choice. Responses are subjected to detailed scoring criteria. Inter-rater reliability was at least  $r = .83$  for interval scales, and  $r > .96$  for categorical scales.

#### 1.4.4. *Competency interview schedule (CIS) (Bean, Nishisato, Rector, & Glancy, 1996)*

The CIS is a 15-item interview designed to assess consent capacity for electro-convulsive therapy (ECT). Patients referred for ECT receive information about their diagnosis and treatment alternatives by the treating clinician, and the CIS then assesses decisional abilities based on responses to the 15 items. Inter-rater reliability was  $r = .95$  for CIS total score.

#### 1.4.5. *Decision assessment measure (DAM) (Wong, Clare, Holland, Watson, & Gunn, 2000)*

Wong et al., working in England, developed a measure that references incapacity criteria in England and Wales (understanding, reasoning, and communicating a choice), based on methodology by Grisso, Appelbaum, Mulvey, and Fletcher (1995). Their instrument also assesses the ability to retain material because it is one of the legal standards for capacity in England and Wales (although not in the U.S.). A standardized vignette regarding blood drawing is used to assess paraphrased recall, verbal recognition, and non-verbal recognition (pointing to the correct information on a sheet with both correct information and distracter/incorrect information); recall and recognition are assessed immediately after disclosure without a time delay.

#### 1.4.6. *Hopemont capacity assessment interview (HCAI) (Edelstein, 1999; Edelstein, Nygren, Northrop, Staats, & Pool, 1993)*

The HCAI medical decision-making component consists of two clinical vignettes; treatment of an eye infection and administration of cardio-pulmonary resuscitation (there are also two vignettes to assess financial capacity). The patient is introduced to general concepts of choice, risk, and benefit, followed by the two scenarios. After discussing the scenarios, patients are asked to recount factual information, explain risks and benefits, state a decision, and explain how the decision was reached. Patients are prompted to provide each of the aforementioned elements with simple, direct questions such as “What are the risks of taking the medication?”, “What are the risks of not taking the medication?”. Inter-rater agreement in a pilot sample ( $N=17$ ) was  $r=.93$  using an exact agreement formula.

#### 1.4.7. *MacArthur competence assessment tool — treatment (MacCAT-T) (Grisso & Appelbaum, 1998)*

The MacCAT-T utilizes a semi-structured interview to guide the clinician through an assessment of the capacity to make an actual treatment decision. It does not use a standardized vignette, although one has been developed for the MacCAT-T for use in research applications (Moye, Karel, Azar, & Gurrera, 2004a, 2004b). Patients receive information about their condition, including the name of the disorder, its features and course. Understanding is assessed by asking patients to “Please describe to me your understanding of what I just said.” Incorrect or omitted information is cued with a prompt (e.g., “What is the condition called?”), and if still incorrect or omitted, presented again. A similar disclosure occurs for the treatments, including the risks and benefits of each treatment alternative. Appreciation is assessed in two sections. The first asks if the individual has “any reason to doubt” the diagnosis, and later whether the treatment “might be of benefit to you.” They are then asked to express a choice and to answer several questions that explicate their reasoning process, including comparative and consequential reasoning and logical consistency. Rating criteria indicate the degree to which the abilities of understanding, appreciation, reasoning, and expression are impaired. Inter-rater reliability was at least  $r=.87$ .

#### 1.4.8. *Perceptions of disorder (POD) (Appelbaum & Grisso, 1992)*

The POD instrument has two parts. The first part, Non-Acknowledgement of Disorder, presents facts of the patient’s actual disorder and then asks the patient to rate agreement with those facts as applying to oneself. The second part, Non-Acknowledgement of Treatment Potential, elicits opinions about whether treatment in general, and medication in particular, might be of some benefit. Low ratings are given when disbelief is based on grossly distorted or delusional premises.

#### 1.4.9. *Thinking rationally about treatment (TRAT) (Grisso & Appelbaum, 1993)*

The TRAT instrument assesses eight functions relevant to decision-making and problem solving: information seeking (asking for additional information), consequential thinking (consideration of treatment consequences), comparative thinking (simultaneous processing of information about two treatments), complex thinking (referencing all treatment alternatives), consequence generation (ability to generate real-life consequences of the risks and discomforts described in the treatment alternatives), consequence weighting (consistent rating of activity preferences), transitive thinking (rating relative quantitative relationships), and probabilistic thinking (rating and understanding probabilities of occurrence). These functions are assessed with a hypothetical vignette and follow-up questions that are framed in terms of the individual advising someone else on making a treatment choice. The last three functions are assessed through standardized tests unrelated to the specific vignette.

#### 1.4.10. *Understanding treatment disclosures (UTD) (Grisso & Appelbaum, 1992)*

The UTD instrument has three versions with three different vignettes: schizophrenia, depression, and ischemic heart disease. Information about the disorder and its treatments is presented in either an uninterrupted or element (a paragraph at a time) disclosure format. Understanding is assessed through ratings on paraphrased recall and recognition. Of note, the POD, TRAT, and UTD are precursor instruments for the MacCAT-T. They are described separately here as we will review studies that are based on these instruments.

### 1.5. *Additional standardized assessment methods*

A few studies do not use specific named instruments, but are based on standardized vignettes and questions that presumably could be replicated by other investigators. Research by Schmand, Gouwenberg, Smit, and Jonker (1999) uses a vignette based on the work by Sachs, Stocking, and Stern (1994) that describes physical therapy or surgery for a hip fracture. Nine questions approximate an assessment of the four decisional abilities. There is also a standardized vignette for consent to a medication research trial.

Fitten, Lusky, and Hamann (1990) and Fitten and Waite (1990) employ three standardized vignettes: treatment for insomnia, a procedure for diagnosis of pleural effusion, and resuscitation in the context of chronic illness. Follow-up questions address the patient's understanding of the condition, the nature and purpose of the proposed treatments and their risks and benefits, and the "quality" of the patient's reasoning process.

## 2. **Empirical studies of medical decision-making capacity**

### 2.1. *Relation of capacity instruments to neuropsychological tests*

#### 2.1.1. *Understanding*

Several studies have considered the relation of the four decisional abilities to neuropsychological measures using univariate correlation or multivariate regression, generally in older samples. In 29 older adults with Alzheimer's disease (AD) (Marson, Chatterjee, Ingram, & Harrell, 1996), understanding (on

CCTI) was best predicted by the Dementia Rating Scale (DRS) conceptualization and confrontation naming ( $R^2 = .70$ ). Another study (Dymek, Atchison, Harrell, & Marson, 2001) with 20 older adults with Parkinson's disease (PD) found understanding (CCTI) was predicted by performance on an executive battery and DRS memory ( $R^2 = .68$ ). Generative naming and confrontation naming showed the strongest correlations with understanding (MacCAT-T) in 20 long-term care older adults with multiple comorbidities (Moye & Karel, 1999). In 43 acutely hospitalized adults, understanding (UTD) was correlated ( $r = .45$ ) with a linear composite of verbal cognitive functioning that combined scores on WAIS vocabulary, similarities, and digit span (Frank, Smyer, Grisso, & Applebaum, 1999). Understanding (UTD) also correlated ( $r = .34-.36$ ) with a similar linear composite of verbal cognitive functioning in 92 adults with depression ( $M$  age 35) and, to a lesser extent ( $r = .12-.33$ ), in 75 adults with schizophrenia ( $M$  age 34) (Grisso & Appelbaum, 1995b).

### 2.1.2. *Appreciation*

The same set of studies found that neuropsychological tests were less consistently and robustly related to appreciation. CCTI appreciation (conceptualized as responses to questions about planning for and projecting long-term outcomes of chosen treatments) was best predicted by generative naming in adults with AD ( $R^2 = .58$ ) (Marson et al., 1996), but was uncorrelated with any neuropsychological tests in adults with PD (Dymek et al., 2001). In univariate analyses, MacCAT-T appreciation (conceptualized as reasons to doubt the diagnosis or treatment benefit) was correlated with attention (digit span) for adults in long-term care (Moye & Karel, 1999), but POD appreciation was not significantly correlated with neuropsychological measures among adults with schizophrenia or depression (Grisso & Appelbaum, 1995b).

### 2.1.3. *Reasoning*

In these same studies, CCTI reasoning (indexed as the total number of rational reasons provided) was best predicted by verbal fluency and DRS initiation/perseveration in older adults with AD and controls ( $R^2 = .36$ ) (Marson, Cody, Ingram, & Harrell, 1995) and by an executive battery in older adults with PD ( $R^2 = .45$ ) (Dymek et al., 2001). Univariate analyses found correlations between reasoning on the MacCAT-T (a series of questions comparing and contrasting reasons for choice including generating everyday consequences of treatment alternatives) and working memory (digits backward) in long-term care residents (Moye & Karel, 1999), and between TRAT reasoning and a WAIS verbal composite in adults with schizophrenia ( $r = .37-.39$ ) and depression ( $r = .27-.30$ ) (Grisso & Appelbaum, 1995b). WAIS verbal performance was not significantly correlated with reasoning in adults undergoing acute medical hospitalization (Frank et al., 1999).

### 2.1.4. *Expressing a choice*

The relation of neuropsychological measures to expression of choice is more difficult to ascertain, given ceiling effects (limited variance) on many measures; most adults, even with some impairments, are able to state a choice. Expressing a choice (CCTI) was predicted by simple auditory comprehension in AD ( $R^2 = .44$ ) (Marson et al., 1996) and by DRS memory in PD ( $R^2 = .55$ ) (Dymek et al., 2001). Confrontation naming correlated with expressing a choice (MacCAT-T) in long-term care residents ( $r = .49$ ) (Moye & Karel, 1999).

Expressed as a global score, capacity correlates most highly with language expression, language comprehension, and abstract thinking (Schmand et al., 1999). In another study where capacity was

considered as a total score (on the HCAI), immediate memory best predicted capacity ( $R^2 = .27$ ) (Staats, Edelstein, & Null, 1995).

## 2.2. *Relation of capacity instruments to cognitive screening tests*

In a number of studies (reviewed by Kim, Karlawish, & Caine, 2002) cognitive screening tests such as the MMSE are correlated with instrument-based assessments of capacity; however, the MMSE is only modestly sensitive and specific (Fitten et al., 1990; Kim & Caine, 2002). Cognitive screening has use for suggesting when further capacity evaluation is needed, but is not in itself informative about specific ability deficits (Pruchno, Smyer, Rose, Hartman-Stein, & Larabee-Henderson, 1995).

## 2.3. *Relation of capacity instruments to non-cognitive variables*

Other studies have considered the relationship of non-cognitive variables to consent capacity. In a sample of 43 older ( $M$  age 71) medically or surgically hospitalized patients, Frank et al. (1999) found that experience with advance directives and life sustaining treatment, and attitudes towards life sustaining technology, best predicted understanding (UTD — heart disease vignette), whereas educational level best predicted reasoning (TRAT — heart disease vignette). Grisso and Appelbaum (1995b) found that understanding (UTD) was associated with symptom severity in adults with schizophrenia, but not in adults with depression. Socioeconomic status was also correlated with understanding scores for adults with schizophrenia and depression, and with one measure of reasoning (TRAT) in adults with schizophrenia. Symptom severity was not correlated with reasoning in adults with schizophrenia or depression.

## 2.4. *Relation of two or more capacity instruments*

One important indicator of construct validity is the extent to which instruments purporting to measure the same concepts agree with one another. HCAI capacity scored “leniently” (naming a risk or a benefit to justify choice) was best predicted by TRAT probabilistic thinking and vocabulary scores in 50 long-term care residents. HCAI total score was correlated with scores on UTD uninterrupted disclosure ( $r = .48$ ) and UTD element disclosure ( $r = .66$ ) in 60 acutely hospitalized adults (Dellasega, Frank, & Smyer, 1996).

In a study comparing the assessment of four decisional abilities by three instruments (CCTI, MacCAT-T, HCAI) with a multi-trait multi-method (MTMM) matrix, the ability of understanding demonstrated good convergent validity (in MTMM this means correlations of understanding as assessed by different measures are higher than correlations of different abilities by the same or different measures) (Moye et al., 2004a, 2004b). In the same study, evidence for the convergent validity of appreciation was poor; while that for reasoning and expressing a choice was fair and mixed, respectively (Moye et al., 2004a, 2004b).

## 2.5. *Relation of capacity instruments to clinical judgment*

Studies comparing test-based and clinician-based evaluations of capacity typically employ threshold instrument scores and categorical (intact capacity/impaired capacity) clinical judgments. Fitten and Waite (1990) found poor agreement between an instrument-based assessment emphasizing recall and



physician-based determinations in 25 acutely ill hospitalized elderly adults. Physician-based and instrument-based ratings disagreed in 28% of the patients, and physicians were more likely than the instrument to rate patients as having intact capacity. Similar results were found in long-term care residents (Bean et al., 1996; Fitten et al., 1990).

Etchells et al. (1999) found slightly higher agreement rates (83–95% of area under ROC curve) comparing an instrument-guided interview (ACE) to clinician rating in 100 adults admitted for medical or surgical interventions. Carney et al. (2001) found moderate to excellent agreement ( $\kappa = .58$ – $1.0$ ) comparing an instrument-based assessment of capacity (CAT) to a psychiatrist's judgment. In a study examining which instruments best predict clinical determinations, Pruchno et al. (1995) found a moderate correlation between instrument-based and clinical assessment of capacity ( $r = .45$ – $.60$ ), with MMSE and UTD understanding best predicting clinical judgments.

## 2.6. Group differences

### 2.6.1. Schizophrenia

The findings concerning capacity assessment in adults with schizophrenia are mixed. Grisso and Appelbaum (1995a) found 75 adults with schizophrenia impaired relative to controls on understanding (UTD), appreciation of disorder or benefits of treatment (POD), and reasoning (TRAT) using mean comparisons. However, only 28% of patients actually were impaired on understanding, 23% were impaired in appreciation, and 24% were impaired on reasoning (Grisso & Appelbaum, 1995a), indicating that the poor group performance was due to very poor performance in a minority of patients. Another study (Wong et al., 2000) found that mean decision-making capacity was not impaired relative to controls in 21 adults with schizophrenia or schizoaffective disorder, although 10% did perform in an impaired range. These discrepant findings may reflect differences in sample characteristics, difficulty level (the Wong assessment focused on understanding a relatively low risk procedure), and power (the Wong study had a smaller sample size).

### 2.6.2. Dementia

A number of studies have found that the consent capacity of individuals with cognitive impairment is reduced compared to healthy controls (Kim, Caine, Currier, Leibovici, & Ryan, 2001; Marson, Cody et al., 1995; Marson, Ingram et al., 1995; Moye et al., 2004a, 2004b; Schmand et al., 1999; Wong et al., 2000). In mean comparisons of specific decisional abilities (CCTI), adults with mild AD were not impaired relative to controls on expression of choice, but were impaired for understanding, reasoning, and appreciation (Marson, Ingram et al., 1995). When specific decisional abilities were assessed by CCTI, HCAI, and MacCAT-T in adults with dementia of heterogeneous etiologies, subjects were impaired on understanding (CCTI, HCAI, and MacCAT-T), appreciation (CCTI only), and reasoning (CCTI and MacCAT-T) in mean comparisons with controls (Moye et al., 2004a, 2004b).

Categorical comparisons using norm-based cut-offs for the CCTI found that 33% of patients with mild AD scored in an impaired range ( $\geq 2$  standard deviations below normative mean) on appreciation, 53% on rational reasons, 100% on understanding, and 13% on evidencing a choice (Marson, Ingram et al., 1995). Rates were higher for adults with moderate AD. In a similar study using norm-based references for CCTI, HCAI, and MacCAT-T, 9–23% of adults with mild dementia scored in an impaired range ( $> 1.5$  standard deviations below the normative mean) on understanding, 2–24% on appreciation, 0–17% on reasoning, and 2–11% on expressing a choice (Moye et al., 2004a, 2004b). Marson, Annis,

McInturff, Bartolucci, and Harrell (1999) noted that loss of task (difficulty projecting oneself into the story), non-responsive answers, and loss of detachment (confusion over the hypothetical nature of the task) characterize capacity impairment in dementia.

### 2.6.3. Institutionalized or hospitalized

Several studies have evaluated adults in long-term care without regard to specific diagnosis and found high rates (44–69%) of capacity impairment (Barton, Mallik, Orr, & Janofsky, 1996; Fitten et al., 1990; Pruchno et al., 1995; Royall, Cordes, & Polk, 1997). Fitten and Waite (1990) compared consent capacity in controls and acutely hospitalized elderly patients without neurologic or psychiatric histories. Understanding was impaired in inpatients relative to controls, indicating that at least transient capacity impairments may be present in patients who are not medically stable. Dellasega et al. (1996) found suboptimal decisional abilities despite good global cognitive function in 60 acutely hospitalized but medically stable older patients, providing further support for the idea that decisional abilities may be compromised during acute medical crises.

### 2.7. Test–retest reliability

Two types of test–retest reliability are of interest: that in healthy controls (i.e., normative samples) and that in patient populations. Good short-term test–retest reliability in controls is an important measure of the instrument's ability to consistently measure a trait over time, and is an essential basis of validity. However, an instrument may not demonstrate high test–retest reliability in patient groups due to fluctuating mental status in those patients, i.e., valid causes of trait instability. Nevertheless, it is also important to study and consider factors relating to fluctuating capacity within patient groups.

Studies generally have found adequate inter-scorer reliability and internal consistency reliability of instruments, but test–retest reliability has rarely been investigated. Grisso et al. (1995) reported statistically significant 2-week test–retest reliability scores ranging from .47 to .80 for understanding and .68 for reasoning in controls, with similar findings in adults with schizophrenia and depression, despite changing scores on the BPRS and BDI. Dellasega et al. (1996) found high 3- to 9-day test–retest correlations ( $r = .64-.75$ ) for understanding (UTD) and overall HCAI capacity ( $r = .85$ ) in 60 medically hospitalized adults.

### 2.8. Reliability between clinicians

There are few empirical studies of the inter-rater reliability of clinical capacity assessment. Marson, McInturff, Hawkins, Bartolucci, and Harrell (1997) found low agreement ( $\kappa = .14$ ) between five physicians with different specialty training who provided dichotomous capacity ratings of adults with AD based on the videotaped administration of instrument-based assessments (MMSE and CCTI). Agreement improved when physicians were trained to evaluate specific legal standards ( $\kappa = .48$ ), but there was still considerable variability (Marson, Earnst, Jamil, Bartolucci, & Harell, 2000). Physicians appear to inconsistently weight different cognitive abilities in capacity assessments, emphasizing either naming, conceptualization, or memory (Earnst, Marson, & Harrell, 2000). Moreover, ratings may vary by specialty (psychiatry, neurology, and geriatrics) (Marson, McInturff et al., 1997). Cognitive impairment may influence clinicians' assessments of capacity differently, depending on the clinician's personal rating style (Marson, Hawkins, McInturff, & Harrell, 1997). Another potential source of

Table 1  
Healthy control group samples on consent capacity instruments

Instrument	<i>N</i>	Age ( <i>M</i> )	Education ( <i>M</i> )	Female (%)	Non-white (%)	Author
UTD	249	34–55 <sup>a</sup>	b	36–55 <sup>a</sup>	7–46 <sup>a</sup>	Grisso and Appelbaum (1995b)
POD	249	34–55 <sup>a</sup>	b	36–55 <sup>a</sup>	7–46 <sup>a</sup>	Grisso and Appelbaum (1995b)
TRAT	249	34–55 <sup>a</sup>	b	36–55 <sup>a</sup>	7–46 <sup>a</sup>	Grisso and Appelbaum (1995b)
Vignettes <sup>c</sup>	176	81	9.2	60	<sup>d</sup>	Schmand et al. (1999)
CCTI	88	72	14.0	50	10	Moye et al. (2004a, 2004b)
HCAI	88	72	14.0	50	10	Moye et al. (2004a, 2004b)
MacCAT-T	88	72	14.0	50	10	Moye et al. (2004a, 2004b)
Vignettes <sup>c</sup>	25	71	11.9	<sup>d</sup>	<sup>d</sup>	Fitten and Waite (1990)
DAM	20	53	<sup>d</sup>	45	<sup>d</sup>	Wong et al. (2000)
CCTI	15	71	14.1	<sup>d</sup>	<sup>d</sup>	Marson, Ingram, et al. (1995)

<sup>a</sup> Values range because subjects were aged matched to one of three patient groups.

<sup>b</sup> No education level provided, but socioeconomic status (education+occupation) is given.

<sup>c</sup> Study describes consent capacity as measured by standardized vignette, although no instrument name is provided.

<sup>d</sup> No information available.

evaluator bias lies in the observation that incapacity may be more frequently diagnosed in treatment-refusers than in treatment-acceptors (Bean et al., 1996).

### 2.9. Normative properties

While detailed normative data are not yet available for any of these instruments, many studies include control sample data that can be used for mean comparisons as shown in Table 1. Sample size ranges from 15 to 249; education ranges from 9.2 to 14.1. Most samples are older adults. Information on race and ethnicity is provided in only two reports.

## 3. Research on information processing and aging

There is considerable evidence for adult developmental differences in how information is processed and decisions are made. Key aspects of this literature are summarized below. These findings have implications not only for considering how capacity relates to cognition, but for the design of capacity research, development of capacity instruments, and data interpretation. Specifically, most capacity assessment methods focus on explicit, deliberative cognitive processing methods while failing to account for implicit, less conscious processing that may nevertheless be utilized in valid decision-making.

### 3.1. Working memory and processing speed

Cognitive aging researchers have approached the study of decision-making through several hypotheses that focus on fundamental elements of decisional tasks. For example, Hasher and Zacks (1988) attributed age differences in decision-making to diminished ability to attend to relevant information and to inhibit the interference of irrelevant information. Thus, the ability to control what information enters, and what is retrieved from working memory, may diminish with age or cognitive

impairment. Salthouse (1992, 1996) argues that age-related declines in complex task performance parallel reductions in working memory and information processing speed (Salthouse & Babcock, 1991). When older adults attempt a complex task with multiple steps, the slowed processing can affect the later steps through failure to complete earlier ones. Thus slowed processing speed can affect working memory and decisional tasks even when speed is not manifestly required (Park, 2000).

### *3.2. Information seeking and importance*

Individuals may vary in how actively they seek information and how they rate the importance of each fact. On average, older adults seek or consider less information before making decisions (Johnson, 1990; Meyer, Russo, & Talbot, 1995; Streufert, Pogash, Piasecki, & Post, 1990) and make decisions more quickly (Meyer et al., 1995). Some of these differences may color ratings of decision-making quality. For example, Zwahr, Park, and Shifren (1999) rated the logical aspects of decision rationales, and found higher ratings in participants who made the most comparisons among treatments. Yet we do not know how logic ratings relate to the authenticity of the treatment choice for the individual. Lower information seeking and more rapid parsing of information into important (to be remembered and used) and unimportant (to be discarded and not used) categories may be a compensatory approach to decision-making in the face of diminished cognitive resources.

### *3.3. Decision-making modality*

Yates and Patalano (1999) characterized three general modes of decision-making: analytic, rule-based, and automatic. The analytic mode, involving step-wise comparisons of risks and benefits, requires the most time and cognitive resources. However, as individuals gain experiences with certain decisions, there is less need to depend on analytic or controlled processing (Yates & Patalano, 1999). The rule-based or heuristic mode, which uses rules as shortcuts in the complex decision-making process, is intermediate in its speed and use of cognitive resources and may be viewed as a simplification strategy (Finucane, Alhakami, Slovic, & Johnson, 2000; Kahneman, Slovic, & Tversky, 1982). The automatic mode (Shiffrin & Schneider, 1977) refers to decisions in which analytic or rules strategies are not evident; it operates without awareness and requires few cognitive resources (Titov & Knight, 1997). Reliance upon rule-based or automatic processing may enable adults with diminished cognitive resources to compensate for these as compared to the analytic modality. However, a compensatory process cannot be assumed. Experts often evolve complex rule-based, then automatic decision-based processes that are quite effective but may be difficult to articulate to others. The difficulty articulating such processes may be reflected in a lower number of “rational reasons” named for making a decision, which may give the evaluator an incorrect impression that valid reasons are not really there. Expertise gained with experience may lead to highly efficient decision-making although it may not be patently “logical” (Snyder, 1994).

## **4. Research concerning individual differences in medical decision-making**

There is a vast literature describing how patients without cognitive or psychiatric impairments make medical decisions. While this literature is not specific to legally defined consent capacity, it has

implications for how research in this area should be approached. Research concerning key variables that influence medical decision-making is summarized below. To date, these variables have not been well-integrated into standardized decision-making capacity assessment tools.

#### *4.1. Quality of life*

One major construct that has been studied with respect to individual differences in medical treatment decision-making is “quality of life” (Birren, Lubben, Rowe, & Deutschman, 1991). In this paradigm, individuals are asked to evaluate various treatment options with respect to the impact they are likely to have on activities or abilities they view as central to their quality of life. Specifically, ratings of valued life activities or goals are related to evaluations of certain scenarios as states or fates “worse than death” (Ditto, Druley, Moore, Danks, & Smucker, 1996; Lawton et al., 1999; Pearlman et al., 1993). These ratings predict hypothetical treatment choices (Ditto et al., 1996). Ideally, assessments of decision-making capacity should include a determination of whether an individual’s treatment choices are consistent with his/her conceptions of quality of life.

#### *4.2. Experience, cohort, race, culture, and religion*

Life experience influences medical treatment decisions in that individuals of different backgrounds may find certain information more salient or meaningful (Karel, 2000). For example, African-Americans are more likely to choose life-sustaining medical treatments, with less concern about “quality of life,” than Caucasian Americans (Caralis, Davis, Wright, & Marcial, 1993; Eleazer et al., 1996; Hopp & Duffy, 2000). Cultural and religious values and beliefs may be critical determinants of an individual’s approach to medical decision-making (Garrett, Harris, Norburn, Patrick, & Danis, 1993; Klessig, 1992), as in the belief held by some that life must be supported at all costs. An individual’s experiences with illness or caregiving also influence the medical decisions they make (Allen-Burge & Haley, 1997; Collopy, 1999; Karel, Powell, & Cantor, 2004). For example, dementia caregivers may be less likely than non-caregivers to endorse life-sustaining interventions when asked to consider hypothetical scenarios (Allen-Burge & Haley, 1997). Life experience may be an especially strong predictor of decision-making in older adults, who tend to focus more on interpersonal and experiential elements of problems than younger adults (Blanchard-Fields, 1996).

#### *4.3. Desire for input from others*

Cultural, generational, and personality differences influence the extent to which control over treatment decisions is desired. For example, older cohorts are more likely to assume that family members or physicians will make medical decisions for them, and therefore take a less active role in seeking illness-related information, having been socialized during a time when patients had less active involvement in medical decision-making (Beisecker, 1988; Degner & Sloan, 1992; High, 1988; Petrisek, Laliberte, Allen, & Mor, 1997). Moye and Karel (1999) noted this tendency in their older research subjects, who seemed reluctant to participate in medical decision-making capacity discussions. This difficulty was evident in responses such as “I place all the decision-making in the doctor’s hands where it should always be, never tell him falsely of things; so a long time ago I placed myself in the hands of the doctor” (other qualitative examples appear in the article). Many non-western cultural groups, including Asian-

and Hispanic-Americans, believe that the individual patient should not be burdened with diagnostic or prognostic information and/or that decision-making responsibility belongs to, or is shared with, the family (Blackhall, Murphy, Frank, Michel, & Azen, 1995; Hornung et al., 1998).

#### *4.4. Locus of control*

Persons also differ in the extent to which they believe their own actions or decisions will have an impact on health outcomes, as compared to the influence of powerful others or chance; this point of view is often referred to as “health locus of control” (Wallston, Wallston, & DeVellis, 1978). The health locus of control construct has genetic and environmental determinants (Johansson et al., 2001), and predicts many aspects of health care decision-making and behaviors across diagnostic and cultural groups (Astrom & Blay, 2002; Engleman & Wild, 2003; Fowers, 1994; Wardle & Steptoe, 2003). Many persons see themselves as having less control of health and healthcare decisions, and thus prefer a collaborative style of decision-making in which they consider the risks and benefits of different treatments actively with the help of loved ones, doctors, clergy, or others (Deimling, Smerglia, & Barresi, 1990; Mezey, Kluger, Maislin, & Mittelman, 1996; Puchalski et al., 2000; Singer et al., 1998). Some decision-making styles may influence an individual’s motivation to participate in, or even the perceived relevance of, a decision-making capacity assessment.

#### *4.5. Consideration of others*

Most medical decisions are made within a social context (Rolland, 1994). Families are intimately affected – practically and emotionally – by patients’ medical treatment decisions, and may therefore seek to influence decision outcomes. The family’s emotional, practical, and financial resources for coping with illness, caregiving, grief, and uncertainty will affect how they interact with and influence the patient (Hardwig, 1990; Rothchild, 1994). Similarly, patients are often very concerned about the impact of their illness and treatment on loved ones, and older adults in particular often express concern about being a burden to their families (Karel & Gatz, 1996). Therefore, salient interpersonal concerns may influence a patient’s approach to medical decision-making, even if the individual is making the decision alone and without input from others.

### **5. Research concerning factors affecting informed consent**

Several lines of research have considered how disclosure procedures affect comprehension during the informed consent process, with the ultimate aim of enhancing comprehension of important information. This research is not specific to medical decision-making capacity, but has implications for the design of instruments created to assess consent capacity.

#### *5.1. Format*

Formats that are more structured, organized, uniform, and brief improve understanding of diagnostic and treatment information, as do simplified and illustrated guides (Dunn & Jeste, 2001). Early research (Stanley, Guido, Stanley, & Shortnell, 1984) found that older adults were less accurate in reporting

critical content information disclosed during informed consent, and that performance improved when consent forms were left available for subsequent reference (Taub, Baker, Kline, & Sturr, 1987). These findings are supported by cognitive aging research that finds environmental aids (e.g., cues for the retrieval of relevant information) reduce demands on cognitive resources subserving working memory. In contrast, tasks that require effortful processing without such supports are more likely to reveal age-related impaired performance ( Craik, 1994; Craik & Byrd, 1982; Craik & Jennings, 1992).

### *5.2. Framing*

Decisions are influenced by the way information is presented. This framing effect (Tversky & Kahneman, 1981) reveals non-rational behavior (Von Neuman & Morganstern, 1947). McNeil, Pauker, Sox, and Tversky (1982) showed that participants who learned that 10% of patients die from surgery and 0% die from radiation were less likely to choose surgery compared to those who were presented with information that 100% of patients immediately survive radiation and 90% immediately survive surgery. Thus, participants are most likely to choose the more positively framed outcome despite identical outcome probabilities. This effect has been demonstrated in a wide range of populations (Kuhberger, 1998), including older adults asked to make medical decisions regarding life-threatening (Mazur & Merz, 1993) and less threatening outcomes (McKee, 2001).

## **6. Summary of the empirical foundations of consent capacity evaluation**

Based on this review of research, what aspects of clinical evaluation of consent capacity are well supported and which aspects of assessment have little or no empirical foundation?

One line of research has studied the relationship of scores on capacity instruments to neuropsychological performance variables. While some specific neuropsychological tests are statistically significant predictors of variance in certain decisional abilities, these relationships vary according to population, the neuropsychological battery employed, and the capacity instrument used. Given these differences, it is difficult to compare findings across studies. The construct of understanding appears to have the most robust relationship to neuropsychological test performance, whereas appreciation is least strongly related to neuropsychological test performance. One possible explanation for these differences is that understanding is most akin to the abilities assessed by standard cognitive testing, whereas appreciation entails a level of abstraction or personalization not captured by traditional cognitive tests. It is worth noting that, while cognitive screening tests are correlated with capacity impairments, they are not sensitive or specific.

The relationship of specific psychiatric symptoms and individual decisional ability deficits has not been well studied and deserves further attention. As a broad generalization, it appears that greater overall severity of clinical deficits is associated with more decisional ability impairment.

Some studies suggest that socioeconomic status and education affect capacity instrument scores. These associations are problematic; an instrument should measure capacity with fairness, i.e. regardless of income or education, because otherwise it is likely to inject a source of bias into the assessment that may undermine the integrity of the assessment process.

Another challenge confronting researchers in the field of capacity research is the lack of a clear consensus regarding the conceptualization and operationalization of decisional constructs. Limited

studies of construct validity indicate that there may be some consensus on the assessment of understanding, associated with lexical knowledge and verbal memory, but no clear consensus on how to conceptualize or operationalize the concepts of reasoning and appreciation. Research regarding the ability to express a choice is more difficult to interpret due to ceiling effects in many populations, i.e., this ability is not likely to be impaired until the advanced stages of an illness.

The lack of a real “gold standard” for capacity assessment hampers the establishment of valid assessment instruments. Only a handful of studies has measured agreement between instrument-based and clinician ratings of capacity, and these indicate that, despite a high overall correspondence between the two methods of assessment, a considerable proportion of patients are assessed as having capacity by physician judgment but without capacity by instrument assessment. Notably, this rating discrepancy occurs most often with treatment-acceptors, implying a systematic rater bias with important ethical ramifications. Rating inconsistencies between these methods may reflect differences in reliability or validity, reliance on distinct data sources, or other as yet unrecognized factors.

The clinical context for the decision-making also appears to impact capacity assessment outcome. There is considerable variability in capacity ratings among patients with similar diagnoses, and among patients receiving similar levels of medical care. This supports the notion that capacity is not predicted by diagnostic or functional status alone. Further, specific sample characteristics including disease subtype, stage, and treatment status are likely to be associated with divergent findings. Definitive conclusions are precluded by the rarity of studies that apply similar methodologies across multiple well-defined patient groups (as done by [Grisso & Appelbaum, 1995b](#)). It appears unlikely that population-based generalizations about decision-making capacity will ever provide useful information in the capacity assessments of individual patients.

The psychometric properties of the instruments are not well understood. Test–retest reliability is greatly under-studied in both normal and patient populations. Intra-individual variability in capacity assessment–reassessment outcomes has important clinical and legal implications, since capacity is generally assumed to be relatively unchanging over short periods of time. A better understanding of the intrinsic variability within this functional domain is necessary for optimal application of current legal standards. For example, what is an appropriate time frame within which a capacity assessment should be conducted so as to be pertinent to a medical decision that has to be implemented? In addition, while most research teams can achieve good inter-scorer reliability with their own instruments, the inter-rater reliability of these instruments in the hands of practicing clinicians not involved in the research project is modest to disappointing.

Research regarding medical decision-making in non-impaired populations helps to broaden the empirical knowledge base concerning consent capacity. This research suggests that individual differences in healthcare values and decision-making preferences may influence treatment choices and may color clinician perceptions of consent capacity. For example, an individual’s values may impact the weighing of risks and benefits in a manner not explicitly credited by some scoring systems or appreciated by individual clinicians. Further, some individuals may appear to have diminished capacity due to decision-making styles that defer to the recommendations or concerns of significant others. The complex role of individual differences in decision-making, and a lack of consensus regarding whether and how to incorporate these in capacity evaluations, may explain some of the low reliability of capacity determinations.

Informed consent and information processing research is also relevant to improving the assessment of decisional capacity in elderly adults. This research shows that decision-making capacity evaluations



aiming to optimize decisional abilities should utilize disclosure formats that are simplified and guided to enhance understanding. These may closely mimic good doctor–patient dialogues where information is presented in a manner that maximizes patient participation, as compared to a test-like situation where a patient is required to memorize information. Capacity evaluations should not neglect to consider the impact of framing, order, and phrasing on the decision-making process. In addition, capacity evaluation should consider the age-appropriateness of, and the cultural background for, decision-making styles. For example, methods of scoring that emphasize the quantity of information recalled may penalize individuals who are lower in information seeking, or who quickly sort and discard less relevant information. As another example, procedures that call for rational manipulations of risks and benefits may penalize individuals who make valid decisions in a more automatic or rule-based approach using expertise gained through life experience.

An awareness of the subtle and complex factors that influence medical decisions in unimpaired adults has implications for how we conceptualize and craft instruments designed to improve the assessment of medical decision-making capacity in cognitively impaired patients. Unfortunately, normative studies of capacity assessment are limited. We do not yet know enough about how variables such as values, beliefs, experience, ethnicity, procedural variables and processing styles impact capacity assessment, and what constitutes normal variability in decision-making styles as it relates to capacity. For example, given the evidence for differences in decision-making approaches, are the TRAT concepts of comparative, consequential, and complex thinking appropriate measures of reasoning for all individuals of diverse ages and ethnicity/race?

## **7. Clinical recommendations**

How then should practitioners proceed in the assessment of consent capacity if taking a strict view of the empirical foundations of consent capacity? First, there appears to be an emerging consensus within the United States that consent capacity entails four decisional abilities: Understanding, Appreciation, Reasoning, and Expressing a choice. Capacity evaluation must also incorporate the broader statutory components of incapacity including diagnosis, cognitive or psychiatric symptomatology, and risk of harm, weighed in the context of ethical principles of beneficence and autonomy (Moye, 1999). A broad consensus supports these general tenets of consent capacity evaluation.

In assessing consent capacity, should practitioners use forensic assessment instruments, that is, instruments developed to specifically assess consent capacity? Although currently available instruments show some promise, they should be used with awareness of the limitations of each instrument, and with the knowledge that a score on an instrument is not intended to supplant clinical judgment. Instruments are useful in that they provide examples of how to conceptualize and operationalize the aforementioned decisional abilities. In selecting instruments for use as resources, it seems most prudent to select instruments developed for the population being assessed. In this vein, the MacCAT-T and other Grisso and Appelbaum instruments may be most useful for psychiatrically disturbed populations, the CCTI may be most useful for demented populations, and the HCAI may be most useful for more impaired adults in long-term care settings. In some cases, instruments may be selected based on the appropriateness of the content (e.g., the CIS when assessing capacity to consent to ECT).

At this point it is not clear which specific cognitive or psychiatric impairments are likely to be associated with diminished decisional abilities, but the overall severity of these deficits is likely to

correlated with capacity impairment. Adults with moderate to severe dementia are likely to have the greatest problems with understanding diagnostic and treatment information, particularly in relation to memory deficits. Research confirms that diagnosis alone does not predict capacity impairment, underscoring the importance of functional assessment.

Whether practitioners use an instrument or interview to assess capacity, empirical evidence indicates that information should be disclosed in a manner that is appropriate to the individual's educational level, in a format that is as simple and organized as possible, and in conjunction with visual cues (e.g., information sheets). Practitioners can utilize the research on individual differences in information processing and age-related changes in decisional styles to guide capacity assessments.

Practitioners may also rely upon this empirical literature to inform questions beyond those concerning the assessment of the four decisional abilities that may nevertheless impact performance on these abilities. Specifically, the patient may be asked about perceptions regarding quality of life, familial or cultural preferences for how decisions are made (input from family and input from practitioners), and vital everyday activities that serve to add meaning and quality to life. These questions can provide an essential context for interpreting the results of capacity assessments. The literature is very clear that there are potential differences in decision-making styles associated with cohort, culture, and religion, and that these are key areas for follow-up inquiry when individuals do not give the expected answers to questions in capacity assessments. More detailed information on capacity and values assessment can be found in a number of resources that review assessment methods and tools (Grisso, 2003; Karel, 2000; Moye, 1999).

## **8. Research recommendations**

The empirical foundations of consent capacity can be improved by studies that address the following aspects of capacity evaluation.

### *8.1. Construct validity*

It is difficult to draw coherent conclusions from the empirical literature due to the heterogeneity of definitions and measures of decisional abilities. Studies that investigate the construct validity of instruments are most needed. These studies should rigorously evaluate how decisional abilities (e.g., understanding, appreciation, reasoning, and expressing a choice) are defined and operationalized on tests. We cannot assume that various conceptualizations and operationalizations are comprehensive or valid for all populations, or that because an instrument purports to measure a decisional ability that it does. More work is especially needed for the concept of appreciation; is appreciation best thought of as insight, foresight, or judgment and is appreciation impaired in different ways in different patient populations?

### *8.2. Criterion validity*

Research is needed to evaluate the relation between decisional abilities and other variables to establish the criterion validity of instruments, and more broadly to provide empirically grounded theoretical models of the relation between decisional abilities and various predictor and moderator variables. In

considering cognitive predictors of capacity, it will be helpful to utilize broad neuropsychological batteries and multivariate approaches. Similarly, it will be useful to study the relation of specific psychiatric impairments with individual decisional ability deficits.

Another important goal for research is to define better the relation between instrument-based and clinical assessment. Our ability to explain correspondence (or lack thereof) between these two methods of assessment will enhance the empirical underpinnings of both. Similarly, studies that compare the correspondence of clinical judgments made by different clinicians are very much needed.

A final area for criterion validity studies concerns the predictive validity of instrument-assessed capacity today with future performance when making medical decisions in real life.

### *8.3. Reliability*

Although much of the research regarding decisional capacity focuses on questions of validity, it is crucially important to understand and improve the test–retest, inter-rater, and internal consistency reliability of these assessments. There is almost no research to establish the basic aspects of reliability of new instruments in normative samples. Without knowledge of reliability in unimpaired populations we cannot interpret the results of reliability and validity studies in impaired populations with confidence. Differing reliability may explain some of the observed variability in existing validity studies.

### *8.4. Integration of capacity research with the literature on decision-making in normal groups*

If research regarding consent capacity can be related to larger conceptual frameworks concerning normal individual variability in how medical decisions are made, the interpretation of capacity scores in atypical cases will be facilitated. Future research should consider the role of values, such as quality of life, experience, desire for input from others, health locus of control, and interpersonal concerns. Cohort, cultural, religious, or ethnic differences may explain some variability in obtained capacity scores, and in some cases indicate the inappropriateness of a particular capacity assessment method in certain populations.

Similarly, future research on consent capacity can draw much from examination of information processing research. Assessment approaches that assume explicit analytic-type processing may unfairly jeopardize individuals who make decisions through more implicit approaches. Normative studies of performance on capacity instruments should describe discrete levels of performance and also relate these to the above variables, so that we can understand the range of decision-making approaches in non-impaired populations and have a more comprehensive basis against which to compare clinically impaired individuals.

## **9. Conclusion**

The number of older adults with chronic illness is increasing, and so, inevitably, is the number of cognitively impaired adults who will need to make complex medical decisions. When the consent capacity of an older adult is questioned, his or her autonomy and ultimate treatment is likely to hinge on a clinician's assessment of decision-making capacity. As such, there is an urgent need to improve the measurement of consent capacity in adults with neuropsychiatric disorders in a manner that is reliable,

valid, and age appropriate. The past 10 years has seen a burgeoning interest in consent capacity research, building on the introduction of various capacity instruments. This research, combined with related lines of research regarding decision-making in unimpaired adults, provides some guidance for current clinical evaluation and a good foundation for further study.

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