

Assessment of Healthcare Decision-making Capacity

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Abstract

It is often necessary for neuropsychologists, clinical psychologists, and other healthcare professionals to assess an individual's capacity to consent to treatment related to healthcare. This task can be challenging and requires a delicate balance of both respect for individuals' autonomy, as well as the protection of individuals with diminished capacity to make an autonomous decision. The purpose of the present review is to provide an overview of the conceptual model of decisional capacity as well as a brief summary of some of the currently available instruments designed to help evaluate medical decision making. In addition, current empirical literature on the relationship between neuropsychological abilities and decision-making capacity is discussed and a brief set of recommendations is provided to further aid clinicians or consultants when they are required to complete the ethically important but difficult task of making determinations about healthcare decision-making capacity.

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Assessment of Healthcare Decision-making Capacity

Among the various forms of civil consent capacity, healthcare consent capacity is important for the primacy to which it directly affects the right to decide what happens to one's own body. The crux of the bioethical quandary in the assessment of healthcare decision-making capacity involves a potential tension between two components of the ethical principle of "respect for persons." This concept has been most clearly described in reference to research ethics, but is equally applicable to healthcare ethics. Specifically, there is a generally recognized ethical duty to respect individuals as autonomous agents with the right to decide what happens (and does not happen) to their own bodies (Beauchamp & Childress, 2001), but there is also a duty to protect those with diminished capacity for autonomous decision making (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979). Without the protection and consideration of those with diminished decision-making capacity, there is a risk of "abandoning patients to their 'rights'" (Hafen, 1976). A prototypic example is an acutely suicidal person whose danger to self does not reflect his/her long-standing values or preferences, but rather the distortions frequently seen in an acute severe depressive, psychotic, and/or manic episode. Whether as clinical provider or in a consultation role, the neuropsychologist or professional tasked with assessing such an individual's healthcare decision-making capacity is presented with a very high stakes question, as the harm associated with false-positive and false-negative errors are both high.

For health and mental healthcare professionals, assessing an individual's capacity to consent to treatment is a necessary, if generally implicit, part of every encounter. That is, treatment cannot be provided unless the patient or a legally authorized representative has given his/her valid informed consent. Although precise data on common practice are not available, formal assessment of healthcare decisional capacity probably arises most frequently when a person refuses recommended treatment.

In other words, we suspect that in actual application, the issue of consent capacity tends to be discussed explicitly not so much in terms of capacity to consent but capacity to dissent/refuse treatment. But the absence of active consideration of consent capacity among those who are assenting to treatment is ethically problematic too. The latter is of particular concern in situations involving options about which reasonable people might disagree depending on their specific values or preferences. For example, none of the existing treatments for prostate cancer is risk or side-effect free, but the risk:benefit considerations vary among options, and the values individuals place on these risks and benefits may differ widely (O'Callaghan et al., 2014). Although decisional capacity is most frequently thought of in reference to patients with serious mental illness or dementia, the problem in other contexts may be more widespread than generally appreciated. For example, in a comprehensive review of studies of rates of healthcare decisional capacity across different settings and populations, Sessums, Zembrzaska and Jackson (2011) found 26% of medical inpatients lacked decisional capacity.

Unfortunately, the validity of unstructured determinations of capacity is problematic. Previous studies have shown that even the most skilled medical professionals may face difficulty when making capacity determinations, often leading to frequent disagreements and low inter-rater reliability (Braun, Gurrera, Karel, Armesto, & Moye, 2009; Kitamura, 2000). For example, Marson, McInturff, Hawkins, Bartolucci, Harrell, (1997) compared the healthcare decision making capacity judgments of five experienced physicians who watched videotaped competency interviews of 29 patients with mild Alzheimer's disease (AD) and 16 normal comparison (NC) subjects. Although there was excellent inter-judge agreement (98%) among the physicians in regard to the capacity status of the NCs, the agreement rate in regard to the capacity status of the AD patients was only 56%. Note that these findings were based on experienced physicians watching video-taped interviews; even lower agreement rates might have resulted if each physician in the study had conducted an independent interview with each patient. False-negative errors are also problematic. In their review of the relevant empirical literature, Sessums et al. (2011) found physicians recognized incapacity among only 42% of those medical inpatients determined as lacking healthcare decision-making through more formal assessments.

Fortunately, inter-judge reliability and validity of capacity determinations can be readily improved by provision of specific education regarding the legal standards for healthcare decision making capacity, and incorporation of a structured instrument designed to guide capacity interviews/assessments in accordance with the relevant legal standards (Marson, Earnst, Jamil, Bartolucci, & Harrell, 2000). Thus, in part to update an earlier review, our group provided in a book chapter (Palmer, Savla, & Harmell, 2012), below we provide an overview of both the legal standards for healthcare decision-making capacity and existing structured instruments. Given the inherently cognitive nature of deciding about healthcare, we also consider the role and limitations of neuropsychological data in capacity assessments and the role of various cognitive functions in specific aspects of the decision-making task.

Four Component Model of Decisional Capacity

Capacity for healthcare is generally defined in terms of four dimensions or criteria: (a) Understanding, (b) Appreciation, (c) Reasoning, and (d) Expression of a Choice (Grisso & Appelbaum, 1998a; Roth, Meisel, & Lidz, 1977). These components were originally identified through review of case law and legal standards of varied stringency that had been used by the courts in various jurisdictions to operationalize competency for healthcare decision making. However, they are now generally recognized as different dimensions of the overall construct as all four must be present for a person to be deemed capable of making healthcare decisions.

“Understanding” refers to the ability of the individual to comprehend the information being disclosed in regard to his/her condition as well as the nature and potential risks and benefits of the proposed treatment and alternatives (including no treatment). In operationalizing assessment of capacity assessment, it is important that the psychologist ensure that he/she is assessing the person's actual comprehension, e.g., as evidenced by an ability to describe the information in his/her own words, rather than the mere ability to parrot-back the words described by the psychologist or to read them verbatim off of a printed consent form.

The “Appreciation” component of decision-making capacity involves the ability to apply the relevant information to one's self and own situation. For example, an individual experiencing an acute manic episode may demonstrate intellectual understanding of what bipolar disorder and mania are, and the risks and benefits of mood stabilizing medications as treatment of acute mania, as well as the risks of forgoing treatment. However, if the very presence of a manic episode (which can include a lack of illness insight) causes an individual with intellectual understanding of bipolar disorder and its treatment to fail to appreciate the personal risks of refusing treatment, he/she might be deemed as incapable on that basis (Cairns et al., 2005; da Silva et al., 2015). The same may occur in the context of some forms of acquired brain injury or any other disorders associated with impaired insight (Ham et al., 2014).

The “Reasoning” component of healthcare decision making refers to evidence that the person’s decisions reflect the presence of a reasoning process, e.g., ability to engage in consequential and comparative reasoning and to manipulate information rationally. Historically, some legal standards also referred to the “reasonableness” of the decision. As noted by Roth et al. (1977), the emphasis on the latter was “on an outcome rather than on the mere fact of a decision or how it has been reached” (p. 281), but it is not generally included among contemporary definitions of capacity.

The fourth component, Expression of a Choice, can itself be deceptively complex. At its most basic level, it simply refers to the ability to communicate a decision. However, some authors have also emphasized the notion of a “clear and consistent” choice. For example, Grisso and Appelbaum (1998a) note:

[Some patients] are able to speak but seem unable to choose – to make up their mind. Thus patients might be considered unable to Express a Choice if, during several consecutive days, they are so ambivalent that they can neither commit to a choice nor assign the decision to someone else. In other cases, patients may vacillate between consent and refusal for medical procedures, thereby producing a clinical stalemate (p. 36).

Note that in addition to explaining the importance of making and communicating a consistent choice, the above quote from Grisso and Appelbaum also alludes to another concept, capacity to appoint a proxy. The latter is a concept that has been gaining increased attention both in the context of research consent (Kim et al., 2011) and healthcare (Moye, Sabatino, & Weintraub Brendel, 2013) but has yet to be widely incorporated into clinical practice or the law. In brief, the idea is that even a patient who lacks capacity to validly consent/dissent to treatment may retain sufficient capacity to appoint a person they trust to help them with the decision. Notably, although the standard consent model emphasizes an individual making a choice in isolation and/or in partnership with the clinician, in most aspects of everyday life, people commonly consult with trusted others for help with making choices. This model of decision making clearly warrants further attention.

The above four-component model of capacity is not without its critics. In particular, there have been some concerns expressed that it is overly “cognitive” and does not sufficiently attend to issues such as authenticity, patient values, or the impact of affect or emotions (Karel, 2000; Karel, Gurrera, Hicken, & Moye, 2010; Kontos, Querques, & Freudenreich, 2015; Mackenzie & Rogers, 2013). However, at least at present, the above model predominates the contemporary definition of what it means to be “decisionally capable” both in terms of healthcare and in term of other civil capacities.

One important caveat regards the distinction between assessment of capacity and a competency determination. Competence/incompetence is a legal term, and a determination of incompetence to make healthcare decisions is the outcome of a formal legal/court procedure. As part of that legal process, the court will generally solicit and consider expert testimony from a neuropsychologist, psychologist, or other qualified mental health professional who has conducted an assessment of the patient’s decisional capacity. But the outcome of a clinical assessment of a patient’s decisional capacity is not synonymous with a determination of a patient’s legal competence status. The latter is a decision made by the court, not the clinician. That caveat noted, legal adjudication of every patient seen by a clinician is not feasible prior to initiation of treatment, yet the clinician is ethically and legally responsible for making certain that each patient is giving valid informed consent. Part of what defines valid consent is that the person has the capacity to use the information provided to make an authentic decision. Thus, even when there is no reason to anticipate need for a formal court proceeding, the clinician is expected to consider a patient’s decisional capacity. A psychologist/neuropsychologist can have two roles in this regard: (a) he/she may be the clinical care provider and assessing the patient’s capacity for the clinical procedures he/she is initiating in that role or (b) he/she may be acting as a consultant for another clinician, that is, asked to provide an expert opinion regarding the decisional capacity of the patient of another healthcare provider. The latter may be particularly likely in those cases in which legal adjudication of competence status is anticipated.

Instruments Designed to Evaluate Medical Decision Making

There have been a number of prior reviews of structured instruments for the assessment of healthcare decision-making capacity (Dunn, Nowrangi, Palmer, Jeste, & Saks, 2006; Lamont, Jeon, & Chiarella, 2013; Palmer, Savla, et al., 2012; Sturman, 2005). An additional review is currently available electronically on the Cochrane library website and contains useful information for psychologists about available capacity instruments (Hein, Daams, Troost, Lindeboom, & Lindauer, 2014). However, an update on the latter website noted that the review was subsequently withdrawn because “there is currently no clear diagnostic gold standard to compare the reviewed diagnostic tests to making it impossible to assess sensitivity and specificity of measures”(Cochrane Database of Systematic Reviews, 2015, unpaginated). If held as an absolute criterion, the latter concern is applicable to the field in general and reflects some of the difficulties inherent in psychometric validation of decision-making capacity instruments. Readers should keep this caveat in mind in both selecting and interpreting results from any particular capacity assessment instrument.

In a prior review, we identified 11 instruments that provide for assessment of all four components of healthcare decision-making capacity (Palmer, Savla, et al., 2012). In preparing this review, we conducted an updated search of the empirical literature but identified no additional comprehensive instruments of healthcare decision-making capacity that have been published in the interim period (In both reviews we excluded instruments that did not measure all four components detailed earlier). Full details of the development and psychometric properties of each of the instruments are available in the reviews cited above, as well as the original published articles introducing each instrument. However, to aid readers in selecting among available instruments, we provide a brief overview of these instruments.

A key decision point in developing a measure of consent capacity is whether to use standardized vignettes or to allow for tailoring of item content (and therefore operationalizing the definition of specific “correct responses”) to the decision at hand. Standardization is a key attribute of validating psychometric instruments, and a relative lack of standardization due to flexible item content potentially affects basic psychometric properties such as inter-rater and test–retest reliability, as well as predictive or concurrent validity (Anastasi & Urbina, 1997). In brief, in the absence of full standardization, comparison of psychometric properties across contexts becomes questionable. There are several published instruments that employ standardized vignettes to assess healthcare decision making (Cea & Fisher, 2003; Edelstein, 2000; Grisso, Appelbaum, Mulvey, & Fletcher, 1995; Marson, Cody, Ingram, & Harrell, 1995; Moye et al., 2008; Schmand, Gouwenberg, Smit, & Jonker, 1999; Vellinga, Smit, Van Leeuwen, Van Tilburg, & Jonker, 2004). The details of the latter instruments are available in prior reviews cited above, as well as the original published articles for each. These instruments can be very useful for studies of factors affecting capacity to consent to treatment. However, a key problem with the use of such instruments in the context of clinically assessing decision-making capacity within individual patients is the inherent contextual nature of the construct. For example, for a person experiencing a severe depressive episode, the relevant question would not be his/her ability to make decisions in general, but something akin to whether to consent to electroconvulsive therapy, pharmacologic treatment, psychotherapy, hospitalization or outpatient treatment, refusal of any active treatment, or some combination of such options. The key point is that healthcare decision-making capacity is an inherently context-specific construct referring to the individual’s capacity to make a choice about the specific decision at hand (Dunn, Palmer, & Karlawish, 2007; Grisso & Appelbaum, 1998a). Similarly, a cognitively impaired person may lack capacity to consent for treatment when the procedures or the risk:benefit considerations are complex but may retain sufficient capacity to consent to a simple/straightforward and/or low-risk treatment decision (Appelbaum & Grisso, 1988). Thus, assessment of consent capacity is ideally conducted within the context of the actual decision the individual is being asked to make.

There are only four published instruments designed to tailor presented information to the specific decision at hand and all employ structured or semistructured interview-based formats. These four instruments include: (a) the MacArthur Competence Assessment Tool for Treatment (MacCAT-T; Grisso & Appelbaum, 1998a, 1998b; Grisso, Appelbaum, & Hill-Fotouhi, 1997) (administration time 15–20 minutes); (b) Competency Interview Schedule (Bean, Nishisato, Rector, & Glancy, 1994) (administration time not reported); (c) Structured Interview for Competency and Incompetency Assessment Testing and Ranking Inventory (Tomoda et al., 1997) (administration time 20 minutes), and (d) Capacity Assessment Tool (Carney, Neugroschl, Morrison, Marin, & Siu, 2001) (administration time not reported). These instruments contain standard sets of items (such as an item disclosing and assessing the individual’s understanding of the nature of his/her disorder) and scoring guidelines, but the specific content (e.g., a description of the specific disorder that the individual has and the proposed treatment, and therefore the responses that will be considered correct) are to be tailored to the situation at hand.

One caveat in employing the tailored instruments is the difficulty with standardization. Standardization is a key attribute of validating psychometric instruments (Anastasi & Urbina, 1997). Flexible item content potentially affects basic psychometric properties such as inter-rater and test–retest reliability, as well as predictive or concurrent validity. In brief, in the absence of full standardization, comparison of psychometric properties across contexts becomes questionable. Given the inherent contextual nature of the construct of healthcare decision-making capacity and the needs for standardization, there is no simple answer to this quandary. Users of any particular instrument need to consider the limitations imposed by the selected approach.

Another consideration in selecting and interpreting instruments is whether they are actually measuring the same constructs. There is some evidence that while the understanding subscales of various instruments show good correspondence, the agreement between several measures’ subscales of reasoning, appreciation, and expression of a choice is suboptimal (Gurrera, Karel, Azar, & Moye, 2007). The key for the psychologist or other clinician conducting a capacity evaluation is to consider the specific item content in light of the presenting question and whether that content is relevant to the targeted ability being assessed.

Neuropsychological Abilities and Healthcare Decision Making

In addition to the use of structured capacity assessment instruments such as those described earlier, clinical assessment of healthcare decision making often also includes consideration of the individual's general cognitive functioning, including performance on cognitive screening measures such as the Mini Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975) or Montreal Cognitive Assessment (MoCA; Nasreddine et al., 2005), and/or a more comprehensive neurocognitive test battery. Beginning in the mid-1990s, Marson and colleagues reported seminal empirical studies of the association of neuropsychological performance to healthcare decision making, primarily in AD and other dementias (Marson, Cody, et al., 1995; Marson & Harrell, 1999; Marson, Ingram, & Harrell, 1993). As part of this work, Marson (2001) proposed a simple cognitive model of the healthcare decision-making process, noting:

Consent capacity may be conceptualized as consisting of three core cognitive tasks: comprehension and encoding of treatment information; information processing and internally arriving at a treatment decision; and communication of the treatment decision to a clinical professional...short-term memory ability is relevant to consent capacity because impaired learning and short-term recall will limit the amount of encoded information available for further processing...receptive language measures are relevant to capacity to consent because of their sensitivity to reduced comprehension of treatment-related information. Conceptualization and executive function measures are important to consent capacity because of their relevance to organized processing of treatment information. Measures of judgment and reasoning are equally important as they make possible a patient's rational weighing of all this information and his/her internal determination of a treatment choice. Measures of expressive language ... may be important because of their relevance to actually communicating the treatment choice (p. 273).

We subsequently provided further theorizing on the role of specific cognitive domains to each component of healthcare decision making (Palmer, Savla, et al., 2012). The key word in the preceding sentence is “theorizing” as, for reasons elaborated below, the empirical literature does not provide a basis for drawing firm conclusions about the role of specific cognitive domains on specific aspects of healthcare decision making. Nonetheless, we believe these rational theorizations may have clinical utility in reasoning about the role of specific cognitive domains in healthcare decision-making capacity, thereby guiding assessment and intervention efforts, so we will briefly reiterate those theories here.

Understanding likely requires both receipt of information (presumably dependent on both attention and receptive language skills), as well as the ability to temporarily store the information in active consciousness (working memory) in order to process/think about that information. Genuine comprehension, beyond mere ability to parrot-back the words, is also likely affected by crystallized verbal knowledge and health literacy (Amalraj, Starkweather, & Nguyen, 2009; Nutbeam, 2008). We presume a role for health literacy based on the general principles of schema theory. Schema theory is a notion from the broader psychological literature (supported by substantial empirical data), which suggests that a preexisting body and structure of relevant knowledge generally facilitates less effortful processing of new information, making it less dependent on active/limited information processing resources (Bransford & Johnson, 1972; Norman & Shallice, 1980; Schank, 1980). Appreciation involves application of information to one's self and one's own situation, and may thus draw on self-referential cognitive/psychological processes. As we noted in our prior review (Palmer, Savla, et al., 2012), self-referential processing may be construed as a form of “executive functioning,” although the latter term itself refers to a diverse array of more specific processes, so it would be critical to consider whether a specific test of executive functioning actually measures self-referential abilities. Under the four-component model of decision-making capacity reviewed earlier, reasoning is generally conceptualized as the presence of reasoning processes, such as the ability to envision and compare potential consequences of various options (Grisso & Appelbaum, 1998a; Roth et al., 1977). Thus, reasoning may draw on both working memory (to keep the information in active awareness/consciousness), and various executive functions such as abstraction, and planning or foresight for envisioning consequences. Finally, to make and express a choice, one must be able to disengage from information processing and actually come to a conclusion. Such disengagement may involve the “mental flexibility”/“shifting” aspects of executive functions (Miyake et al., 2000; Savla et al., 2012), and then communication of the choice made requires some form of expressive language function.

Representative Research

Over the past two decades, a large number of studies have examined the association of specific neurocognitive domains to healthcare decision making. We have provided two prior comprehensive reviews of this empirical literature (Palmer & Savla, 2007; Palmer, Savla, et al., 2012). Some general conclusions can be drawn from these reviews. Foremost, cognitive deficits tend to be the strongest predictor of healthcare decision-making capacity, even in disorders for which other symptoms might be expected to predominate. For example, in a study by our research group of capacity to consent to antipsychotic

medications among 59 middle-aged or older people with schizophrenia or schizoaffective disorder, we found a nonsignificant correlation, $r = -.17$, between general psychopathology and the MacCAT-T Understanding subscale, whereas that for general cognitive dysfunction (measured with the Mattis Dementia Rating Scale total score (Jurica, Leitten, & Mattis, 1991)) and MacCAT-T Understanding was $r = .49$, $p < .001$ (Palmer, Dunn, Appelbaum, & Jeste, 2004). Similar results have been consistently found in reference to the relative association of cognition versus psychopathology with capacity to consent to research among people with schizophrenia or bipolar disorder (Carpenter et al., 2000; Palmer, Dunn, Depp, Eyler, & Jeste, 2007; Palmer & Jeste, 2006; Stroup et al., 2005).

Some of the cognitive domains that appear to be commonly predictive of decisional capacity include episodic memory, confrontational naming, working memory, and executive functions, as well as psychomotor speed. Of note, recent research suggests that it may be important to not only attend to level of cognitive impairment but also to intra-individual variability in neurocognitive test performance. That is, greater intra-individual variability in test performance within a battery of neuropsychological tests may itself be predictive of greater risk of worse decisional capacity (Gurrera, Karel, Azar, & Moye, 2014).

Although cognitive abilities frequently have strong correlations with the components of capacity to consent to treatment, there is no clear pattern of differential associations that emerges between specific cognitive abilities and specific components of decisional capacity. For example, for the understanding component, different samples have reported highest correlations for episodic memory (Okonkwo et al., 2008; Palmer et al., 2004), executive functioning (Dymek, Atchison, Harrell, & Marson, 2001), verbal memory, and phonemic fluency (Gerstenecker et al., 2015), and between processing speed and episodic memory (Okonkwo et al., 2008). For appreciation, the highest correlations have been reported for working memory (Palmer et al., 2004), processing speed (Okonkwo et al., 2008), and episodic memory (Okonkwo et al., 2008). The reasoning component has similarly shown mixed findings across different samples with strongest correlations reported in working memory (Moye & Karel, 1999; Palmer et al., 2004), executive functions (Dymek et al., 2001; Marson, Chatterjee, Ingram, & Harrell, 1996), and episodic memory and expressive language (Okonkwo et al., 2007). It should be noted that in the preceding sentence, we intentionally used the term “highest correlations” rather than “strongest correlations.” The significance in the difference of magnitude of various correlations was rarely tested although there are established methods for testing the magnitude of differences between bivariate correlations (Cohen, Cohen, West, & Aiken, 2003). Indeed, one interpretive limitation in determining the relative importance of specific cognitive dimensions to decisional capacity from the existing empirical literature, including some of our own studies (Palmer et al., 2004, 2013), is the common use of stepwise regression. Stepwise regression can be useful in developing actuarial prediction models and in exploratory analyses for developing hypotheses about potential key factors, but the degree to which one can draw definitive conclusions about the relative importance of the independent variables related to the dependent variables is extremely limited (Thompson, 1995; Whittingham, Stephens, Bradbury, & Freckleton, 2006).

Notably, evidence for differential associations between specific cognitive domains and specific dimensions of decision-making capacity also tends to be marred by psychometric limitations in the available instruments. A basic tenet of scale development is that, all other things being equal, longer scales tend to be more reliable (presuming the additional items are correlated with the other items in the scale and with the target construct being measured) (Anastasi & Urbina, 1997). From this perspective, the available comprehensive measures of healthcare decision making (i.e., those which assess Understanding, Appreciation, Reasoning, and Expression of a Choice) generally have stronger measures of Understanding than the other components. For example, the MacCAT-T, which we identified earlier as among the best of available measures, has 13 items on the Understanding subscale but only 2 items on the Appreciation subscale, 4 items on the Reasoning subscale, and the Expression of a Choice subscale consists of a single item. Due to differential psychometric properties of the subscales, one is likely to find stronger correlations between overall (or any specific subdomain of) cognition and Understanding than with other components. There are exceptions in individual studies, but this appears consistent with the general pattern in the empirical literature on the association of cognitive functioning and specific components of decisional capacity (Palmer & Savla, 2007; Palmer, Savla, et al., 2012). But the problems of differential psychometric properties are not limited to the measures of decisional capacity. This issue is also a long-standing concern in establishing differential patterns of cognitive impairment due to uncertainty about the psychometric equivalence of the means by which specific neurocognitive constructs have been measured (Chapman & Chapman, 1973, 2001).

Clinical Recommendations

The previously stated caveats about the limitations of available instruments for the assessment of healthcare decision-making capacity, as well as about the ability to draw firm conclusions about the differential role of specific cognitive deficits in healthcare decision making, should not be interpreted as implying that neither have a role in the assessment of healthcare

decision-making capacity. Rather, we believe the key here is the classic distinction between psychological assessment versus psychological testing (Matarazzo, 1990). Test administration is an invaluable component of assessment, but the skilled psychologist/neuropsychologist has a critical role in evaluating the test results in the larger clinical context. Capacity instruments are designed to be helpful in guiding the capacity assessment, but they are not synonymous with such assessment. For example, the authors of the MacCAT-T intentionally did not provide a “cutoff” score defining capacity/incapacity. As such, the overall assessment of healthcare decision-making capacity should involve additional information, such as the specific nature of the proposed healthcare procedure or intervention, and the risks versus benefits of false-negative versus false-positive errors in capacity determinations within that context. Also included in healthcare decision-making capacity determinations should be interviews with collateral informants who can shed light on the course of the patient’s mental status as well as the consistency of any currently expressed decision with his/her long-standing stated values and preferences, behavioral observations, and record review that may reveal transitory or modifiable environmental and/or intra-individual factors that are acutely impeding better decisional capacity and thereby suggest ways of improving the patient’s manifest decisional capacity level. A useful multipronged model to guide assessment of healthcare and other civil capacity is provided in a freely available handbook jointly prepared by the American Psychological Association and American Bar Association ([American Bar Association Commission on Law and Aging & American Psychological Association, 2008](#)).

Capacity Instruments

Among the four instruments designed to be tailored to the individual situation, the MacCAT-T has been validated in a variety of populations, has demonstrated high reliability and construct validity in a number of contexts, and appears to be the most widely used in studies of healthcare decision-making capacity (Dunn et al., 2006). Unfortunately, to our knowledge, there is no published study of the frequency with which any of the instruments are actually used in applied settings. A Spanish-language version of the MacCAT-T was also recently published (Alvarez et al., 2014). Moreover, the MacCAT-T is one of the few measures to have a detailed manual available to help guide administration, scoring, and interpretation of the instrument.

As noted earlier, there are also a number of published instruments with preset content, i.e., employing a hypothetical vignette approach to decisional capacity assessment. Given the context-specific nature of the construct of decisional capacity, these instruments may be most appropriate for either research on factors influencing decisional capacity or as a standardized supplement to a context-specific interview such as that provided by the MacCAT-T. Those caveats noted, of the decisional capacity instruments’ employing hypothetical vignette scenarios, the Capacity to Consent to Treatment Instrument (CCTI; Marson, Ingram, Cody, & Harrell, 1995) appears to be the most well validated and widely used. The CCTI requires about 20–25 minutes to administer and consists of two vignettes, involving brain tumor and heart blockage. The CCTI vignettes are presented in oral and written format, and the person is asked to imagine he/she has the condition specified in the scenario. After the presentation of each vignette, the written consent is removed and patients are asked a series of questions assessing their consent abilities. The CCTI has been used in a variety of different populations such as individuals with AD, Parkinson’s disease, epilepsy, and traumatic brain injury (Bambara et al., 2007; Dreer, DeVivo, Novack, Krzywanski, & Marson, 2008; Griffith et al., 2010; Martin et al., 2008; Triebel, Martin, Nabors, & Marson, 2009). In addition, age independent and age-adjusted normative data were recently published for the CCTI to assist clinicians in comparing a patient’s performance on the CCTI with that of other adults irrespective of age and/or to same age peers (Gerstenecker, Niccolai, Marson, & Triebel, 2016). To our knowledge, this is the only available instrument with normative data.

In addition to the above recommendations, the particular context or needs of a specific patient or application may make one of the other available instruments a more viable or useful option in certain settings. For example, lengthier instruments that are time-consuming may be inappropriate in acute medical settings when very timely medical decisions are required and/or for use with patients who are easily fatigued. For the latter, the time required to administer a lengthier capacity instrument may interfere with the individual’s sustained attention and engagement in subsequent clinical assessments if they require effort or concentration. Interested readers are referred to prior comprehensive reviews of these instruments for further details, which may help in selecting the instrument most appropriate to their specific need (Dunn, Nowrangi, Palmer, et al., 2006; Lamont et al., 2013; Palmer, Savla, et al., 2012; Sturman, 2005).

One issue with many of the available instruments, including both the MacCAT-T and CCTI, is administration time. For example, the MacCAT-T generally requires 15–20 minutes to administer, and in our experience employing this instrument in a study of healthcare decision-making capacity among people with schizophrenia can sometimes take even longer (Palmer et al., 2004). Sometimes that time is well justified by the gravity or stakes of the treatment decision. But given that healthcare decision-making capacity is of at least implicit relevance to the majority of healthcare encounters, there is a need for brief

screening tools to identify those warranting more thorough assessment. In that regard, members of our research group developed a brief (less than 5 minute) instrument to assess capacity to consent to research, the UCSD Brief Assessment of Consent Capacity (UBACC; Jeste et al., 2007), which has been subsequently modified and used in two studies of capacity to consent to treatment (Burton et al., 2012; Doyle et al., 2016). We originally designed the UBACC to measure the Understanding, Reasoning, and Appreciation components of decisional capacity, but in our validation study we found the UBACC items primarily related to Understanding and Appreciation (Jeste et al., 2007). The extent to which the UBACC or UBACC-T adequately measures the Reasoning component of healthcare decision making is uncertain. Nonetheless, the UBACC-T may have some utility in identifying those patients warranting more comprehensive assessment.

Neuropsychological Assessment

In regard to neuropsychological assessment, we argued earlier that the published literature does not allow empirically based conclusions about the association between specific cognitive deficits and impairment in domains of healthcare decisional capacity. The difficulty in demonstrating such relationships rests in part in the psychometric characteristics of the available instruments, and the limitations of the available instruments may in part reflect the very nature of the construct being targeted. For example, we noted that the MacCAT-T Understanding subscale has 13 items, whereas the Expression of a Choice subscale consists of a single item. The latter is a simpler construct and may not require 13 items for valid assessment. But in either case, the difficulty in empirically demonstrating such relationships on a group level does not mean that neuropsychological assessment has no utility in clinical assessment of those with suspected impaired consent capacity. On the contrary, we believe, guided by rational considerations of the likely impact of specific deficits on the decision-making process, the information from such assessment may be very useful at the individual level in terms of identifying the underlying nature of capacity deficits and planning appropriate remediation efforts (cf. [American Bar Association Commission on Law and Aging & American Psychological Association, 2008](#)).

Conclusions

Psychologists/neuropsychologists faced with evaluating a patient's capacity to consent to (or dissent/refuse) healthcare need to consider all four dimensions of this construct: Understanding, Appreciation, Reasoning, and Expression of a Choice. In a low-risk or simple context, it may be acceptable to have this assessment as part of the informal/unstructured interview, but that discussion and assessment should still be guided by consideration of these four components. In higher risk populations or contexts, explicit formal/structured assessment of healthcare decisional capacity should be considered. In many cases, this assessment may be best guided by inclusion of one of the published instruments reviewed earlier, with the interpretive limitations of each instrument held in mind. That information should be used in the context of a broader assessment of decisional capacity that includes an array of additional information (see [American Bar Association Commission on Law and Aging & American Psychological Association, 2008](#)). In some cases, wherein a patient seems to lack capacity to consent, the reasons for his/her difficulties may not be readily apparent. It is in those contexts where we believe neurocognitive assessment may be helpful in identifying specific cognitive strengths and weaknesses. Although the empirical literature on the association of such cognitive abilities does not permit firm conclusions about differential effects of specific cognitive deficits and specific aspects of decision making, there are rational reasons to expect specific cognitive abilities may be most critical to specific components of the decision-making process, and rational consideration of manifest cognitive deficits may inform remediation efforts.

The latter point is, in our view, critical—a determination of incapacity to decide about healthcare should not be the end of the process. Psychologists need to actively consider what steps may be taken to enhance the capacity of the individual to meaningfully participate in his/her healthcare decision making—whether at the level of legal consent or assent. For example, the use of multimedia consent aids has not yet proven consistently effective in research contexts (Palmer, Lanouette, & Jeste, 2012), but computerized decision aides in treatment contexts have garnered more empirical support. For example, a comprehensive review found positive effects of multimedia consent aids on understanding among 23 of the 37 reviewed studies (Jeste, Dunn, Folsom, & Zisook, 2008). These studies included diverse populations for varied medical assessments and treatments (e.g., psychiatric inpatients, patients with Stage I or II breast cancer, patients scheduled for a colonoscopy, older male veterans from a general medicine clinic being asked to consider advanced directives). Therefore, multimedia tools appear to hold promise as an effective supplement to the way patients receive and process clinically important information. The influence of intra-individual factors, such as fatigue, anxiety, as well as more stable but potentially malleable factors such as health literacy should also be considered. Waiting for transient interfering factors (such as anxiety or fatigue) and/or provision of

further education can sometimes help resolve comprehension issues. In short, even when a person is determined to presently lack healthcare decisional capacity, active efforts should be maintained to involve him/her in treatment decisions to whatever extent possible, including reassessment of capacity as situations or the person's mental status may improve. The potential effects of language and culture have received almost no empirical attention in the informed consent literature, but this too is a dimension important to consider in developing optimal - patient centered - methods of providing the consent process in a meaningful form.

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Conflict of Interest

None declared.

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