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Assessment of Capacity to Consent to Treatment: Challenges, the "ACCT" Approach, Future Directions

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Abstract

Objective—To review approaches to assessing consent capacity in patients with neurocognitive or neuropsychiatric illness; to summarize the rationale behind our structured interview for consent capacity; and to outline questions for future research.

Method—After reviewing legal and clinical literature, and empirically comparing three leading consent capacity instruments, we developed the Assessment of Capacity to Consent to Treatment (ACCT) interview and administered it to adults with dementia (n=20), schizophrenia (n=20), and controls (n=19). Capacity ratings by primary care clinicians and experts blind to the patients' status were obtained for a subsample.

Results—Interscorer reliability was r=.90; internal consistency reliability was .α=96. ACCT scores agreed 82% of the time (kappa = .44; p<.01) with primary care clinician ratings of capacity and 75% of the time (kappa = .50; p<.05) with expert ratings of capacity. Patients with dementia and schizophrenia could express treatment choices but performed worse than controls on measures of understanding, appreciation as problems with foresight, rational reasoning, and values-based reasoning. Only patients with schizophrenia performed worse on a measure of appreciation as problems with distrust.

Conclusion—The method of assessing consent capacity described here has adequate reliability and validity, and may provide a useful starting point for clinicians and researchers. Many questions remain about the nature of consent capacity, its component constructs, and the meaning of instrument versus clinician ratings of capacity. Future adaptations, particularly in the assessment of appreciation and reasoning, and additional studies in more diverse samples, are needed.

Keywords

Capacity; Competency; Consent

Introduction

Diminished capacity to consent to medical treatment is a common concern in older adults with dementia or schizophrenia. Such individuals may have diminished capacity to consent

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to a complex medical intervention but retain the capacity to consent to a relatively simple medical treatment. As such, consent capacity must be evaluated for each specific informed consent situation. In these, capacity should be maximized to the extent possible. Disclosure formats that are more structured, organized, uniform, and brief serve to improve capacity, as do simplified and illustrated guides (Dunn & Jeste, 2001) which are left available for subsequent reference (Taub, Baker, Kline, & Sturr, 1987).

Four standards for decisional incapacity are commonly found in US statutory and case law, used either individually or conjointly (Appelbaum & Grisso, 1988; Drane, 1985; Roth, Meisel, & Lidz, 1977; Tepper & Elwork, 1984). (1) *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 re-stating diagnostic and treatment information. (2) *Appreciation* is 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 (Grisso & Applebaum, 1998). Thus, Appreciation focuses on evaluation of understood information in terms of personal relevance and beliefs. (3) *Reasoning* is the ability to provide rational explanations, or to compare treatment alternatives in a logically or rationally consistent manner. (4) *Communicating a Choice* is the ability to convey a treatment choice.

The reliability of clinical capacity judgments can be unacceptably low. Near chance agreement (56%; kappa = .14) was found among five physicians providing dichotomous ratings of capacity in adults with Alzheimer’s Disease, based on videotapes of an instrument-based assessment (Marson, McInturff, Hawkins, Bartolucci, & Harrell, 1997). Similarly low reliability (kappa = .31) was found among 176 clinicians who rated written case descriptions for capacity (Kitamura & Kitamura, 2000). Agreement was lowest for appreciation and reasoning. Physicians appear to emphasize different cognitive abilities in making personal judgments of capacity, including naming, conceptualization, or memory (Earnst, Marson, & Harrell, 2000; Schmand, Gouwenberg, Smit, & Jonker, 1999).

Inter-rater reliability of physician assessment of capacity may improve when clinicians are trained to assess specific legal standards (Marson, Earnst, Jamil, Bartolucci, & Harell, 2000). Several structured assessment tools have been developed to assist clinicians in directing their assessments to these standards (Kim, 2002; Moye, Gurrera, Karel, Edelstein, & O'Connell, 2006). Most instruments designed to assess consent capacity offer a hypothetical vignette – the patient is asked to demonstrate understanding, appreciation, and reasoning about a hypothetical condition and his or her hypothetical treatment choices. In contrast, some instruments are designed as semi-structured interviews which allow tailoring to the specific consent situation at hand. With these instruments there is good agreement on the measurement of understanding and choice, although current methods of assessing understanding have disproportionately high verbal recall demands (Marson, Chatterjee, Ingram, & Harrell, 1996; Moye, Karel, Azar, & Gurrera, 2004b), and poorer agreement on appreciation and reasoning. Measurement strategies developed to assess appreciation and reasoning in one population may work less well in another.

Goals of this Paper

The purpose of this paper is to describe the development of an interview for the assessment of capacity to consent to treatment which responds to strengths and weaknesses of existing approaches, to report pilot data on its statistical properties, and to elucidate what we have learned in this process. The instrument was developed to address three goals related to perceived shortcomings with existing instruments: (1) to minimize the reliance on memory in the assessment of understanding; (2) to use multiple approaches for the assessment of reasoning and appreciation; (3) to incorporate the assessment of health care values into the determination of capacity. Preliminary evidence for reliability and validity are presented, as are a comparison of results in older adults with dementia versus schizophrenia.

Methods

Development of the ACCT Interview

The Assessment of Capacity to Consent to Treatment (ACCT) interview was developed based on a review of existing instruments (Moye et al., 2006), especially the work of Marson and colleagues (Marson, Ingram, Cody, & Harrell, 1995), Edelstein and colleagues (Staats & Edelstein, 1995), and Grisso and Applebaum (Grisso & Appelbaum, 1998a) and our empirical comparison of their consent capacity instruments (Moye, Karel, Azar, & Gurrera, 2004a; Moye et al., 2004b). Our goal was to create a reasonably brief/time-efficient instrument to assess consent capacity in individuals with either neurocognitive or neuropsychiatric deficits. The instrument is provided in Appendix A.

Applications of the ACCT

The ACCT was developed for research applications, but can be adapted to clinical use. For research, a hypothetical vignette is used to elicit treatment choices for an imaginary condition, as in this project. In clinical applications, the same questions may be used to evaluate capacity for an actual treatment situation. Or, if the individual is not facing a current treatment decision but the care team has questions about the patient’s ongoing capacity to consent to treatment, the hypothetical vignettes can be used.

Components of the ACCT Interview

The ACCT begins with a values interview to elicit values and preferences relevant to medical decisions. Then, through the use of three hypothetical vignettes, the ACCT assesses four decisional abilities: understanding, appreciation, reasoning, and communicating a choice.

Values—Three key values domains relevant to healthcare decision making were identified based on a survey of the literature and pilot studies. The first domain concerns the impact of treatment choices on valued activities and relationships (Karel, 2000; Karel, Moye, Bank, & Azar, 2007; Pearlman, Starks, Cain, & Cole, 2005). A second domain considers the individual’s preferred decision-making style (autonomous, shared, deferred) – specifically whether one prefers to make decisions alone or others (i.e., family, clinicians) or to defer entirely (Blackhall, Murphy, Frank, Michel, & Azen, 1995). A third domain is comprised by views on how one values quality versus length of life, including the influence of religious beliefs on such views (Cicirelli, 2000; Doukas & McCullough, 1991). Items were adapted from existing scales and refined in multiple pilot studies (Karel, et al., 2007).

Vignettes—Three standardized vignettes were developed to represent treatment options for acute illness, chronic illness, or advanced illness. We increased complexity by adding increasing number of facts with each vignette, and by varying the nature of the choice (a comparison of treatment or no treatment versus a comparison of two treatments), and the nature of doctor recommendation (recommendation for one treatment versus no specific recommendation) as shown in Appendix B. The intention of creating three vignettes is that clinicians or researchers could select a vignette whose content or level of complexity was most relevant.

The first vignette has 16 items (6 facts for understanding) and presents a choice of medication or no medication for the treatment of rheumatoid arthritis. The rationale for the first vignette is to describe a condition that involves pain and functional limitations – salient concerns for some people (Karel & Gatz, 1996), with a treatment that could address these symptoms but potentially cause cognitive or affective side effects – salient concerns for others. Thus, the vignette provides a simple choice to take or not take a medication, with each option resulting in risks that may be aversive depending on one's values.

The second vignette, derived from Edelstein et al (Edelstein, 2000; Staats & Edelstein, 1995) has 18 items (8 facts for understanding). The second vignette begins with the description of a stroke and functional limitations as a context for a subsequent decision for or against CPR in the event of cardiac arrest. This vignette aims to potentially reflect decisions related to views on what defines a "quality of life" as well as potential religious influences on choices to intervene to prolong life in advanced illness.

The third vignette presents a choice of toe amputation or femoral-popliteal bypass for a non healing toe ulcer, and is based on our previous studies (Moye et al., 2004a). It has 22 items (12 facts for understanding). The rationale in developing the third vignette is to present a more complex set of treatment options that each present a set of risks and benefits, with no one recommendation from the physician, to be able to more deeply explore individual variability in treatment choices.

Understanding

Existing Approaches: Understanding is typically assessed by disclosing information about a diagnosis and treatment alternatives, then assessing an individual's comprehension by asking the person to paraphrase the information back or to answer specific questions about the content. Empirical analysis finds good content validity (Moye et al., 2004c) and criterion validity (Gurrera, Moye, Karel, Azar, & Armesto, 2006; Marson et al., 1996), but raises a concern that existing approaches may over-emphasize recall memory.

ACCT Approach: The ACCT builds on these approaches but attempts to minimize recall demands to favor comprehension. There are two subscales that refer to the ability to comprehend (a) diagnostic information and (b) treatment information. Information is presented in segments with a written list. Afterwards, the subject is asked to answer general questions, e.g., "what are the risks" "what are the benefits" while referring to the list. The characteristics and sources of the decision making items are detailed in Table 1.

Appreciation

Existing Approaches: Appreciation has been assessed by providing diagnostic and treatment information, then asking the individual if they have any reason to doubt the veracity of the diagnostic information or the potential benefits of treatment (Grisso & Appelbaum, 1998b). Less direct approaches ask the individual to project what they would need to do to plan for the treatment and what would be the likely outcome of the treatment (Marson et al., 1995) or why the physician is recommending treatment (Staats & Edelstein, 1995). More direct approaches ask the individual whether the doctor is trying to incur harm (Bean, 1994; Saks et al., 2002). Empirical studies of these approaches finds poor content and criterion validity (Gurrera et al., 2006; Marson et al., 1996; Moye, et al., 2004a; Moye et al., 2004b) , raising questions as to whether these quite different approaches may be more or less relevant for different populations.

ACCT Approach: Recognizing the potential benefit of different approaches, the ACCT employs two subscales for Appreciation to assess the individual's ability to acknowledge the existence of the disorder or the potential benefits of treatment. The Distrust subscale is geared towards individuals who fail to acknowledge the disorder or potential benefits of treatment because of suspicion towards the doctor or "patently false beliefs" (Grisso &

Appelbaum, 1998b). The Foresight subscale is geared to individuals who fail to acknowledge the disorder or benefits of treatment due to executive-linked difficulties in presuming conditions and future states.

Reasoning

Existing Approaches: Most approaches to reasoning emphasize rationality by asking the individual to identify the risks and benefits or rational reasons (Bean, 1994; Carney, Neugroschl, Morrison, Marin, & Siu, 2001; Grisso & Appelbaum, 1998b; Marson et al., 1995) for their choice, or to compare risks and benefits (Grisso & Appelbaum, 1998b). Some instruments ask the evaluator to rate the logical consistency (Grisso & Appelbaum, 1998b) or adequacy of insight and judgment (Carney et al., 2001). There is moderate content and criterion validity for these approaches (Gurrera et al., 2006; Marson et al., 1996; Marson, Cody, Ingram, & Harrell, 1995; Moye et al., 2004a, 2004b). Further, although some commentators note the importance of evaluating reasoning in light of an individual's personal or cultural values (Berg, Appelbaum, Lidz, & Parker, 2001; Carney et al., 2001; Margulies, 1994), this has not been integrated into standardized assessment approaches.

ACCT Approach: The first subscale of Reasoning approaches assessment of reasoning tied to case law that emphasizes rationality. Two items use different approaches – naming rational reasons and comparing risks and benefits. The second subscale of Reasoning approaches assessment of reasoning using a novel "values standards" for capacity, defined as the ability to justify choices as consistent with one's values. Individuals are asked to explain how the treatment choice affects aforementioned valued activities and relationships.

Communicating a Choice

Existing Approaches: The ability to convey a treatment choice appears relatively straightforward to assess – but the empirical evidence for this standard is somewhat difficult to evaluate because of restriction of range problems (most patient samples in the research literature receive "full credit" for measures of communicating a choice). We conclude that communicating a choice is an ability with good face validity, and a threshold ability – i.e., necessary to then consider the individual's understanding, appreciation, and reasoning about that choice.

ACCT Approach: The first subscale of Communicating a Choice measures the individual's ability to identify the two treatment choices (with prompting for both). The second subscale assesses an individual's ability to select one choice as a desired treatment.

Scoring

The ACCT interview is intended to have a low ceiling – that is, most cognitively normal older adults should be able to provide full or near full credit responses. For understanding items, one point is given for each key fact correctly paraphrased. For appreciation, reasoning, and choice, two points are given for accurate responses; 1 point for vague or ambiguous responses, and 0 points for incorrect responses. Detailed scoring criteria are available from the authors.

For the purposes of statistical comparisons, a summary dichotomous score (has capacity/lacks capacity) was calculated consistent with approaches used in the literature (Marson et al., 1996). First, we determined subscale dichotomous scores for understanding, appreciation, and reasoning based on scores two standard deviations below the control group mean. Then we determined a summary dichotomous score, assigning a rating of "lacks capacity" for individuals who were impaired on any of the decisional abilities. This is consistent with a legal approach in which significant impairment on any ability is sufficient to define incapacity. Communicating a choice was not included in the summary score calculations as it is a “threshold ability” (i.e., as previously noted, restriction of range makes statistical approaches inappropriate). We could only calculate such a summary score for vignette three – which was the only vignette given to our control comparison sample.

Analyses

Reliability—To establish the reliability of our scoring criteria, we examined the agreement between scores obtained by one rater, and scores obtained by a second independent rater while referring to the scoring manual. Since scoring for the values items was self-evident (e.g., participants provided a discrete response), the inter-scorer analyses focused on the scoring of the decisional ability items. We also examined internal-consistency reliability, similarly focusing on the decisional ability items as the values items are not meant to reflect performance or to comprise a scale.

Validity—Capacity is a construct with clinical, ethical, and legal referents. Although a clinician’s opinion is currently the accepted standard for capacity determination, there is no single “gold” standard – as clinical opinion can be quite unreliable (Marson et al., 1997). Thus, studying capacity requires a construct validation approach, where multiple lines of evidence for validity are interwoven (Moye, 1996).

Accordingly, we examined three types of validity. First, we considered the association between scores on the ACCT and cognitive test performance. The instruments would be expected to have a moderate positive correlation as the instruments measure related but different constructs (ACCT assesses specific decisional abilities while cognitive tests assess general cognitive functioning). Second, we considered the association of ACCT scores with clinician ratings. The ACCT and clinical ratings would be expected to have moderate positive association. The degree of association is restricted by the fact that the ACCT is focusing specifically on decision making abilities, whereas clinicians base their ratings on any number of clinical factors considered relevant. Third, we considered group differences as an indicator of validity – namely do patient groups where some degree of incapacity is expected perform lower on the instrument than a cognitively healthy comparison group.

Piloting the ACCT Interview

Recruitment

Patient Samples—Individuals with dementia (n=20) or schizophrenia (n=20) were recruited from the outpatient clinics of the VA Medical Center in Boston. Due to the nature of the VA population, all participants in this study were male. Inclusion criteria were: (a) age 60 years or over; (b) primary language English, and; (c) ability to participate in a one hour interview as judged by clinicians familiar with the patient. Patients in the dementia group carried a clinical diagnosis of dementia. Patients in the schizophrenia group carried a clinical diagnosis of schizophrenia. Participants in the dementia group ranged in age from 65–88 years (M=77.97, SD=6.38); participants in the schizophrenia group ranged in age from 60–93 (M=70.85, SD= 8.68). All participants were white.

Comparison Sample—In order to compare the performance of these patient groups to normative performance, data from a healthy comparison group (n=19) who had completed the third vignette of the ACCT interview for a related study were obtained from a VA Medical Center in Salt Lake City. Individuals in the cognitively healthy comparison group were recruited from primary care clinics; those who carried a clinical diagnosis of dementia or schizophrenia, or who had a MMSE score lower than 26, were excluded. The healthy comparison group ranged in age from 61–83 (M=74.35, SD=6.38).

Procedures

Subject Testing—Cognitive status was assessed with the Modified Mini-Mental State Exam (3MS) (Teng & Chui, 1987). Psychiatric status was assessed with four subscales of the Brief Symptom Inventory (BSI) (Derogatis, 1993): Anxiety, Depression, Paranoia, and Psychosis.

Capacity was assessed with the ACCT interview by trained research assistants. Each protocol was scored by two research assistants; scoring discrepancies were resolved by the principal investigator (JM). For the purposes of examining inter-scorer reliability, 10 protocols were scored by a doctoral level psychologist unfamiliar with the study according to the study manual and compared to the ratings obtained in the study.

The study was approved by the IRB and all subjects provided written informed consent. One patient with schizophrenia had a guardian, and in that case, consent was obtained from the guardian with the patient's assent. All participants were compensated for their time.

Clinician Ratings

Primary Care Provider (PCP) Ratings: Thirty-two of the 40 patients in the dementia and schizophrenia patient groups had a regular primary care clinician who had seen the patient at least twice, and had seen the patient in the past year. Twenty-seven responded to our request to provide a clinical opinion on the patient's medical decision making capacity based upon their clinical experience with the patient. Ratings were provided on a four point scale and dichotomized for the purposes of statistical analyses.

Expert Clinician Ratings: Consensus ratings were provided by majority vote of three experienced clinicians, one geriatrician, one psychologist, and one psychiatrist, with at least 7 years experience in geriatric evaluation, who devote at least 25% of their time to older patients, and who demonstrated the highest inter-clinician reliability in our pilot studies. Ratings were provided for 12 patients with either dementia or schizophrenia on the basis of audio tape recordings of the third vignette in the ACCT interview. Ratings were provided on a six point scale and dichotomized for analyses.

Results

Descriptive Statistics

Treatment Choices—In Vignette One, the majority of the patients with dementia and schizophrenia chose to take the medicine (80% schizophrenia, 95% dementia). In Vignette Two, the majority of both groups chose to have CPR (80% schizophrenia, 70% dementia). For Vignette Three, groups varied slightly in their choices, with individuals in the schizophrenia group less likely to choose amputation. Across groups, 45%, 65%, and 88% of the schizophrenia, dementia, and primary care groups chose amputation, respectively (χ^2=8.42, $p<.08$).

Values—Participants varied in the life abilities/activities they viewed as most important (Table 2). While patient groups did not differ on most of these items, patients in the dementia group were most likely to rate living at home as one of their three most important abilities; patients in the schizophrenia group were least likely to rate having relationships with family and friends as one of their top three priorities. Participants' preferences for autonomous, shared, or delegated decision making varied across individuals but not patient groups (Table 3). There was a general preference for collaborative decision making with doctors and family. The individuals in the schizophrenia group had the greatest variability (largest SD) in these ratings, but there was variability in all groups; for example, 5% of the entire sample wanted to make decisions entirely alone (without input from doctor) while 15% wanted the doctor to make the decision mostly or entirely.

Mean ratings regarding the influence of spiritual or religious beliefs on medical decision making fell between “a little” (1) and “somewhat” (2), with no statistical differences between groups. However, individual ratings within groups varied, with eight (13%) participants saying that religious or spiritual beliefs would influence their medical decisions “completely.” Most individuals rated “quality” as more important than length of life (mean ratings were “mostly true”). Ratings for the desire for medical intervention to prolong life fell in the mid-range.

Capacity Ratings—Eighty percent of the patients with schizophrenia and 75% of the patients with dementia received a dichotomous summary score of “lacks capacity” (Vignette 3). The groups had the same rates of impairment for understanding (35% lacked capacity in each group). Rates of impairment for other abilities were higher, and in each case greater for patients with dementia: appreciation (65% dementia, 55% schizophrenia); reasoning (68% dementia, 45% schizophrenia); communicating a choice (60% dementia, 40% schizophrenia). Decisional abilities were positively correlated across vignettes, ranging from .44−.83 (p<.05).

Reliability

Inter-scorer reliability—Inter-scorer reliability between the scores obtained for the study and those obtained by an independent rater for 10 patient protocols was r =.90 (p<.001) for the total score. Inter-scorer reliability was highest for communicating a choice (r=.98; p<.001), understanding (r=.90; p<.001), appreciation (r=.89; p<.01), then reasoning (r=.68; p<.05). When examining by vignette, inter-scorer reliability was highest for Vignette One (r=.95; p<.001), followed by Vignette Two (r=.83; p<.01), and Vignette Three (r=.76; p<.05).

Internal consistency reliability—Cronbach internal consistency reliability was α =.96 based on all capacity items (n=56) across three vignettes for patients with dementia and schizophrenia. Internal consistency reliability was α =.88 (16 items) for Vignette One, α =.88 (18 items) for Vignette Two, and α =.91 (22 items) for Vignette Three. Internal consistency reliability was highest for understanding (α =.91; 26 items), followed by appreciation (α =.88; 12 items), reasoning (α =.82; 12 items), then communicating a choice (α =.66; 6 items).

Validity

Association of ACCT with 3MS—Total ACCT score for participants with dementia or schizophrenia was moderately correlated with the total 3MS score (r=.47; p<.01). The ACCT was not significantly correlated with total BSI score (r=.25; NS) nor any BSI subscales.

Association with Clinician Ratings—Dichotomous ratings of capacity by the ACCT versus PCPs, for 27 subjects with either dementia or schizophrenia, agreed 74% of the time (kappa = .44; p<.01; n=27). Discrepancies were noted in seven cases where the clinicians found the patients to have capacity and the ACCT did not. ACCT scores were significantly correlated with PCP ratings for reasoning (r=.41, p<.05), but not other abilities.

Dichotomous capacity ratings on the ACCT and consensus ratings by three experienced clinicians, for 12 participants with dementia or schizophrenia, agreed 75% of the time (kappa = .50; p<.05; n=12). Discrepancies were noted in three cases where the clinicians found the patient to have capacity and the ACCT did not. ACCT scores were significantly correlated with expert consensus ratings for understanding (r=.73, p<.01) and reasoning (r=.87, p<.01).

Group Differences on Decisional Ability Subscales—Patients with dementia or schizophrenia performed lower than the healthy comparison group on measures of understanding, appreciation as foresight, and reasoning (Table 4). Patients with schizophrenia performed lower than patients with dementia or the healthy comparison group on appreciation as distrust. Performance was not associated with whether the individual reported having had the medical condition in the past (t=.69; NS) or having made a similar decision in the past (t=1.37; NS).

Discussion

The development of the ACCT interview was based on our comparison of innovative capacity instruments developed by other investigators, to address several goals: (1) the assessment of understanding should focus, to the extent possible, on comprehension of information, not memorization; (2) the construct of appreciation needs further explication, and may have different facets for different populations; (3) the assessment of reasoning should allow for individuals who make decisions based on strong underlying values rather than purely rational manipulation of risks and benefits; and finally (4) to facilitate such evaluation of values-based reasoning, that the capacity interview should begin with an assessment of relevant values.

The preliminary evidence for reliability and validity of the ACCT is generally good. However, there are significant limitations to these preliminary data, namely, that it was gathered from a small, all-white, all-male sample. Issues of culture, race, and ethnicity are especially important in how individuals may approach treatment decisions. Further, our patient samples were defined on the basis of chart diagnoses which were not independently confirmed. Additionally, our primary care comparison group represents a small sample of older veterans without diagnosed dementia or schizophrenia, but they were not screened medically to rule out for conditions that might impair cognition. As such, the use of these patient scores to provide normative data upon which to derive cut-scores for the patient groups is tentative.

The results raise many questions about the nature of consent capacity, its component constructs, and the meaning of instrument versus clinician ratings of capacity. These questions have been the focus of our research program, and are of great interest to us. However, the data presented here are too limited to answer such questions. As such, we will focus our discussion on the development and psychometric characteristics of the ACCT based on this sample, and describe areas for future study.

Values Assessment

It is critical to begin any assessment of an individual’s medical treatment decision making process by understanding the personal and cultural values underlying those decisions. In practice this likely occurs during a clinical interview with the patient and family, or from having had a long standing treatment relationship with the patient. However, values assessment has not been linked to capacity assessment in the research literature to date. In this study we found that individuals with mild dementia, schizophrenia, and a primary care comparison group could select from a list the life abilities/activities most important to them, and could rate their preferred style for decision making (autonomous or shared) and the influence of various beliefs on decisions. There was considerable inter-individual variability in the ratings regardless of patient diagnosis. The discrete response categories and response cards seemed quite helpful in narrowing in on some of the complex concepts.

Vignette Development

We developed three vignettes representing a range of complexity, and with various treatment choices which might affect different valued activities and relationships. Correlation of decisional ability scores across different vignettes suggests a broad consistency between approaches (correlations on communicating a choice were likely limited by restriction of range), but the fact that correlations were only mid range also indicates that capacity levels vary by decisional complexity.

We felt the treatment situation described in vignette two was the least successful. We thought it was important to offer a context of diminished quality of life, within which the individual would make choices about resuscitation. In our clinical work in long term care, this hypothetical is often quite real. However, in a research interview it seemed to result in an over-abundance of hypotheticals. Understanding how and why individuals make specific life sustaining (or not) treatment choices is important. Continued methodological innovation is needed.

Understanding

Some approaches to assessing understanding have high memory demands. Therefore, we used a cued approach here, where a bulleted list of key facts remained out during the interview. Even with the cued list, patients in the dementia and schizophrenia groups were impaired relative to the primary care comparison group. We noted that some individuals failed to refer to the list in front of them even when cued to do so. The inability to refer to obvious information (assuming literacy) was quite intriguing, and may be a reflection of dysexecutive problems. However, overall rates of impairment on dichotomous ratings were low compared to other abilities, suggesting that the cued procedure maximized performance. However, some subjects referred to facts in a rote manner – unconvincing of comprehension. Thus, it may be helpful to ask patients some yes/no or multiple choice questions to clarify their degree of comprehension.

Appreciation

Individuals with schizophrenia were more likely than those with dementia or the comparison group to be impaired on appreciation as measured by distrust, yet both patient groups were impaired relative to the comparison group on appreciation as measured by foresight. This result offers support to the hypothesis that different approaches to measuring appreciation may be more relevant for different patient populations. Specifically, patients with psychotic disorders may be more likely to display disbelief.

However, some individuals were slightly puzzled or even offended by our questions about doubting the doctor. Therefore, a step-wise approach to assessing appreciation might be advantageous. If an initial question about doubts elicits some suspicion about the diagnosis or potential benefits of treatment, follow-up questions could be asked. In sum, appreciation is a complex concept, undoubtedly the most enigmatic of the four decisional abilities. We limited its assessment to four items representing two different approaches to appreciation, as we wanted to keep the length of the assessment brief. In future studies it may be helpful to explore the construct with more items.

Reasoning

Our approach to assessing reasoning was motivated by a concern that measuring only the rational weighing of risks and benefits may fail to capture the range of ways in which individuals arrive at decisions – specifically use of experiential and intuitive decision making based on broad “rules of thumb” or prevailing values (Finucane, Alhakami, Slovic, & Johnson, 2000; Kahneman & Tversky, 1984). In this study, patients with dementia and schizophrenia were impaired relative to our comparison group on both “rational” and “values-based” reasoning.

Unfortunately, our values-based approach to reasoning did not work as well as we had hoped. We carefully constructed the choices in our vignettes to have consequences for potentially valued activities or relationships, and we asked how treatment decisions related to these. However, the matrix of possible treatment consequences to valued activities is broad. Therefore, at times a chosen treatment had no implications for that individual’s most valued activities. Likewise, some participants did not have close relationships with anyone, so the impact of treatment choices on valued relationships was moot. These complexities made scoring more difficult than we imagined, and likely account for the lower inter-scorer reliability for reasoning. Although the assessment of reasoning in terms of values came off with variable success in this research interview, in clinical situations, it still seems important to explore the personal values, wishes, fears, and interpersonal conflicts that may underlie treatment decision making. Focusing only on “rational manipulation” of risks and benefits may overlook otherwise valid reasons underlying treatment choices.

Communicating a Choice

In this study, patients with dementia and schizophrenia were not impaired relative to the comparison group for communicating a choice, and mean scores were near the upper limit. The ability to communicate a choice may be considered a “threshold” ability that most patients with modest neurocognitive or neuropsychiatric impairment can achieve.

Psychometric Issues in Studying Consent Capacity

This study illustrates some of the challenges of establishing the psychometric properties of capacity instruments. In general, standard approaches to establishing reliability are appropriate. In this study we considered inter-scorer reliability and internal-consistency reliability. We did not evaluate test-retest reliability, and few existing capacity instruments do. Obviously, it is difficult to interpret the meaning of variation over time on these instruments if we have not demonstrated short-term consistency of scores in medically stable individuals. Future research must address this gap.

The issue of validity is more problematic. This study finds moderate positive agreement between ratings provided on the ACCT interview and a cognitive screening test, and by two different types of clinician ratings. Which is the gold standard? Each approach has validity and limitations. We were tempted to compare the ratings provided by our primary care clinicians – who had ongoing clinical knowledge of the patient, with our “expert” clinicians – who were blind to the participants’ clinical status but more experienced in capacity ratings, and to comment here on the meaning of the relationship of the clinician ratings with various decisional ability scores. However, our sample size is too small. Future studies with more varied patient populations, and larger numbers of clinician ratings, might explore what factors account for ratings by different clinicians and how these relate to capacity ratings provided by instruments.

Summary

Our rationale for and experience with the ACCT interview are presented here for clinicians and researchers. Preliminary data with 59 research participants demonstrate adequate reliability and validity. Future studies in more sex and race diverse samples are required. Continuing studies to elucidate the values individuals bring to treatment decisions and how these might be woven into the assessment of consent capacity are needed. These preliminary data raise many questions about the nature of consent capacity as assessed by instrument versus clinician ratings, and suggest fruitful areas for further study.

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Appendix A

Assessment of Capacity to Consent to Treatment (ACCT) Interview

Part 1 : Values Assessment

Valued Activities—"The next questions are about what is most important to you in your life, or what makes your life worth living. Please tell me which three things are most important to your life or make your life worth living."

To take care of myself (e.g., bathing, dressing); not have to depend on others for help with daily life.

To walk or move around by myself.

To live at home.

To think clearly about things.

To make my own life decisions (e.g., about health, finances, housing).

To have relationships with family and friends.

To practice my religion or spiritual life (faith, prayer).

To live without significant pain or discomfort.

To do specific activities or hobbies that I enjoy (e.g., reading, tv, gardening). *[ask, "what is it"]*.

Valued Relationships[1]—

Please tell me:		
Do you live:		
Alone	With loved ones	With others
Who are the people who are most important in your life?		
How close are you to them?		
Not at all	Somewhat close	Very Close

"The next questions are about who you like to be involved when you face an important medical decision."

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[1] In our study this item was elicited more informally.

Deference to Doctor—“When you make an important healthcare decision, how much input do you want from the **doctor?”**

I want to make the decision myself.

I want to make the decision mostly by myself.

I want to make the decision together with my doctor.

I want my doctor to make the decision mostly for me.

I want the doctor to make the decision entirely for me.

Deference to Family—“When you make an important healthcare decision, how much input do you want from your **family?”**

I want to make the decision myself.

I want to make the decision mostly by myself.

I want to make the decision together with my family.

I want my family to make the decision mostly for me.

I want the family to make the decision entirely for me.

Influence of Religion/Faith—“When you make an important healthcare decision, how much do your religious or spiritual beliefs influence your decision?”

Not at all, A little, Somewhat, Mostly, Completely

Quality of Life Attitudes—“For this first set of questions, I will read you a statement, and I’d like you to tell me how true or false the statement is for you.”

“The quality of my life is more important than how long I live.”

“If I were very sick, I would like to do everything possible to prolong my life.”

“Living as long as possible is more important than the quality of my life.”

If I were very sick, I would like to let nature take its course.”

Very False, Mostly False, that you Do Not Know, Mostly True, or Very True.”

Part 2. Decision Making Abilities Assessment

General instructions.

If responses are vague, ask for elaboration. If using a standardized vignette and the individual gives examples or reasons outside of the vignette, direct them to the facts in the vignette (e.g., “yes, but in this story what is the benefit of the medication”). If the question asks for two responses (e.g., what are the two choices for treatment) and the individual gives only one response, prompt for another response.

U1. UNDERSTANDING 1: DISORDER—*Give bulleted list of information about the disorder to the patient. Leave the list out during the entire interview for reference.*

“In this next section, I am going to leave out lists of what I am reading. You can refer to the lists if you like.”

If using a hypothetical problem, read this introduction:

"Now, I am going to tell you a story about a pretend or imaginary medical problem. I want you to listen very carefully. After I am finished, I am going to ask you some questions about the problem to make sure you understand it. Okay?

In this story, I want you to imagine you have ___________."

If referring to a real medical problem, read this introduction:

Now, I am going to talk to you about a medical problem you are facing. I want to review with you the basic facts about your medical situation. I want you to listen very carefully. After I am finished, I am going to ask you some questions about the problem to make sure you understand it. Okay?

Right now, the medical problem you have is ___________."

Disclose information about the disorder.

Now, please describe to me in your own words …"

Give credit for facts correctly enumerated. If response is omitted, prompt with questions below. If response is still incorrect or omitted, state the correct response. Repeat or rephrase the question if question misunderstood

u1. Who has this medical problem?

u2. What is the medical problem?

u3. How is it affecting you?

U2. UNDERSTANDING 2: TREATMENT A—*Give bulleted list of information about the treatment to the patient.*

Disclose information about Treatment A.

Now, please describe to me in your own words …"

u4. What does the doctor want you to do?

u5. What are the benefits of the treatment?

u6. What are the risks of the treatment?

u7. What are the risks of not getting the treatment?

A1. APPRECIATION I: DISTRUST

a1. Do you have any doubts that such a medicine might help you? Why/Why not?"

a2. Would you be concerned that the doctor might be trying to harm you? Why/Why not?"

UNDERSTANDING 2: TREATMENT B

If there is an alternative treatment, disclose and inquire in the same manner as Treatment A.

C1. NAMING A CHOICE

c1. What are your choices for treatment (in the story)?

If only one choice is given, prompt, e.g., "what is the other choice".

C2. COMMUNICATING A CHOICE

c2. What would you do?

If no choice provided, prompt for choice, e.g., "if you had to choose, which one would it be".

R1. REASONING 1: RATIONAL—Rational Reasons

r1. "What risks and benefits did you consider when making that decision?

If only one risk or benefit given, prompt, e.g., "what is another one?"

Comparative Reasons

r2. Tell me why ____ seems better than ____.

R2. REASONING 2: VALUES—Impact on Valued Activities

r3. What are the ways that [choice] could affect [activities]? *Ask for elaboration.*

Impact on Valued Relationships

r4. What are the ways that [choice] could affect [person/relationship]? *Ask for elaboration.*

A2. APPRECIATION 2: FORESIGHT

a3. Since you decided to [choice], is there anything you need to do to prepare for it?

If only one thing given, prompt, e.g., "what else might you do to plan?"

a4. Do you believe you might get better without [treatment]?" Why/Why not?"

Appendix B

Assessment of Capacity to Consent to Treatment (ACCT) Interview Vignettes

Vignette 1

In this story, I want you to imagine you have rheumatoid arthritis.

You have a lot of pain in your hands and joints. It is hard for you to take care of yourself.

The doctor wants you to take a medication. The medication involves purchasing prescription medication and taking it twice a day. The benefit of taking the medication is that it will decrease the pain, and make it easier to take care of yourself. The risk of taking the medication is that it might make you confused or drowsy, and depressed. The risk of not taking the medication is that the arthritis will be very painful, and keep you from taking care of yourself. So you see, the medication can help you feel better, but it also has risks.

Vignette 2

In this story, I want you to imagine the condition you have had is called a stroke. You have had a stroke that makes it difficult for you to think and move. You need help to take care of yourself, so you have moved to a nursing home. While in the nursing home, you can still enjoy simple pleasures like seeing family or friends and enjoying tv or music.

In the story, after you have had a stroke and are living in a nursing home, a doctor wants you to say what you would like to do if your heart stops beating. If your heart stops beating, the doctor could order CPR. CPR involves having a doctor or nurse press on your chest to keep the heart beating and blow into your mouth to keep air going to the lungs. The benefit of CPR is that it may save your life. The risk of CPR is that you might end up with brain damage. Also, there is a risk your ribs could be broken from pushing on the chest. The risk of not getting the CPR is that you will probably die. So you see, the CPR might save you, but it also has risks.

Vignette 3

In this story, the condition I want you to imagine you have is a non-healing toe ulcer. A non-healing toe ulcer is an infected open sore that does not respond to medication. It is caused by a lack of blood supply from the legs to the feet. If not treated, the infection may spread and could eventually lead to death.

There are two possible treatments. Now, I am going to tell you about one treatment. The first treatment is surgery on an artery in your leg. The surgery involves an incision all the way down the leg to insert a new artery. The benefits are that it would increase the blood supply to the foot and save your toe. The risks of the surgery are that there is a 5% chance of dying during surgery. Also, you will need help for about 6 weeks while you recover after the surgery.

Now, I am going to tell you about the other treatment. The second treatment is to have your big toe amputated. A surgeon cuts off the toe. The amputation and recovery are quick. The benefits of the amputation are that it would get rid of the infected tissue without major surgery. The risks of the amputation are that after, you would have to use a cane and would have difficulty with balance.

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Table 1

Decision Making Ability Components and Sources of Items

Ability	Subscales	Items[a]	Notes	Adapted from:
Understanding	U1. Disorder	4–8	Each element is disclosed and assessed with questions. A	HCAI (Edelstein, 1999), MacCAT-T
	U2. Treatment	8–16	bulleted list is left out for reference.	(Grisso & Appelbaum, 1998b), Pilot studies
Appreciation	A1. Distrust	2	Doubt about the benefit of treatment; Concerns about harm from doctor	MacCAT-T (Grisso & Appelbaum, 1998b), POD (Appelbaum & Grisso, 1992)
	A2. Foresight	2	Planning for chosen treatment; Projection of status after treatment	CCTI (Marson et al., 1995), CSA (Saks etal., 2002)
Reasoning	R1. Rational	2	Compare and contrast treatments; List rational reasons for treatment	HCAI (Edelstein, 1999), MacCAT-T (Grisso & Appelbaum, 1998b), CCTI (Marson et al., 1995)
	R2. Values	2	Treatment consequences for valued activities; Treatment consequences for valued relationships	Pilot studies
Communicating a Choice	C1. Naming	1	Naming two choices	HCAI (Edelstein, 1999), MacCAT-T
	C2. Communicating	1	Statement of one consistent choice	(Grisso & Appelbaum, 1998b), CCTI (Marson et al., 1995)

[a] The number of items assessed in Understanding varies based on the complexity of the diagnostic and treatment situation. With the standardized vignettes developed for research, the number of facts increases with each vignette.

Table 2

Frequency of “Top Three” Valued Life Activities or Abilities

Item	Overall	Within Subject Group			
		Dementia	Schizophrenia	Comparison	Chi square
To take care of myself (e.g., bathing, dressing); not have to depend on others for help with daily life	40%	35%	35%	50%	1.25
To walk or move around by myself	23%	25%	30%	15%	1.30
To live at home	25%	50%	15%	10%	10.33[**]
To think clearly about things	30%	35%	35%	20%	1.43
To make my own life decisions (e.g., about health, finances, housing)	33%	25%	35%	40%	1.05
To have relationships with family and friends	47%	55%	20%	60%	5.76[*]
To practice my religion or spiritual life (faith, prayer)	28%	15%	40%	30%	3.12
To live without significant pain or discomfort	45%	35%	50%	50%	1.21
To do specific activities or hobbies that I enjoy (e.g., reading, tv, gardening)	20%	20%	20%	20%	0.00

Note. Subjects were asked to select the three things that “are most important to your life or make your life worth living.” Selecting three made later comparisons with treatment consequences more manageable. Percentages reflect the number of subjects in each group who chose that activity as one of three most important abilities.

[*] $p<.05$,

[**] $p<.01$ comparing dementia, schizophrenia, primary care participants.

Table 3

Mean (± SD) Ratings on Decision Making Preferences and Influences

Item	Dementia	Schizophrenia	Comparison	F
Preference for decision making by doctor[a]	2.15 (0.88)	1.85 (0.93)	2.02 (0.60)	0.70
Preference for decision making by family[a]	1.40 (0.88)	1.53 (1.31)	1.75 (0.44)	0.71
Influence of religious or spiritual beliefs on healthcare decisions [a]	1.35 (1.42)	2.10 (1.48)	1.70 (1.49)	1.31
Importance of quality of life (versus length)[b]	6.36 (1.50)	5.56 (2.01)	7.05 (1.15)	4.23 *
Desire for medical intervention to prolong life[b]	3.94 (2.21)	4.05 (1.51)	3.33 (2.22)	0.67

[a] Higher scores indicate higher preference for input from doctor, family, or religion, range 0–4.

[b] Combined score on two items, total range 0–8.

* $p < .05$

Table 4

Mean Group Differences on Decisional Ability Subscales for Vignette Three

	Score Range	Dementia M (± SD) N=20	Schizophrenia M (± SD) N=20	Comparison M (± SD) N=19	F	Post Hoc
Understanding Disorder	0–8	4.25 (1.83)	4.65 (2.18)	6.11 (1.29)	5.61*	A, B
Understanding Treatments	0–16	9.95 (4.71)	9.80 (4.68)	13.16 (2.71)	4.02*	A, B
Appreciation Distrust	0–4	3.75 (0.55)	2.50 (1.50)	3.95 (0.23)	13.71*	B,C
Appreciation Foresight	0–4	2.60 (1.35)	2.25 (1.41)	3.63 (0.68)	6.91*	A, B
Reasoning Rational	0–4	2.75 (1.41)	2.50 (1.47)	3.89 (0.32)	7.44*	A, B
Reasoning Values	0–4	2.60 (1.27)	1.85 (1.23)	3.74 (0.93)	12.16*	A, B
Naming Choices	0–2	1.45 (0.83)	1.25 (0.85)	1.95 (0.23)	5.06*	B
Communicating A Choice	0–2	1.85 (0.49)	1.65 (0.75)	2.00 (0.00)	2.24	

*P<.05

Note: the following letters indicate significant (p<.05) group differences in post hoc analyses using bonferroni correction.

A. dementia group < comparison group

B. schizophrenia group < comparison group

C. schizophrenia group < dementia group