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Assessment of the Capacity to Consent to Treatment (ACCT)

Administration and Technical Manual

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Readers are referred to additional work by Jennifer Moye and colleagues on the topic of capacity

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Chapter 1. Concept of Consent Capacity

Key Concepts

We use the term “capacity” to refer to a dichotomous (yes/no) judgment by a clinician as to whether an individual can make an autonomous treatment decision. In most health care settings, questions of consent capacity rarely proceed to adjudication, unless treatment requiring judicial authorization within the jurisdiction is involved, guardianship is being pursued, or the case is otherwise being litigated (e.g., family conflict). In this manual, we refer to judicial determinations of consent capacity as “competency.” In reviewing the empirical literature, when we refer to understanding, appreciation, reasoning, and expressing a choice, these terms are used specifically in reference to four legal standards for decisional abilities for consent capacity, described in more detail below.

Our work is guided by three assumptions about capacity.

Assumption #1: Capacity as a construct is complex

A primary assumption of our clinical and research work is that capacity, as a construct, is complex and even enigmatic. Its roots are in case law rather than in a scientifically based theoretical framework, and it is applied in clinical settings. It has multiple components and determinants. Different clinicians arrive at different conclusions about capacity in similar cases. Unlike almost any other clinical assessment process, the outcome impacts not just the course of treatment, but an individual’s ethically and legally sanctioned rights to self-determination.

Assumption #2: Capacity is challenging to assess in some patients

Sometimes, a patient’s incapacity to make a medical decision is obvious, such as when a patient with severe neurological impairment is unable to convey a treatment choice. In other cases, a patient’s capacity is mildly impaired, but shared decision making is appropriate—for example, if the treatment is low risk (e.g., initiating aspirin for prevention of stroke risk in coronary artery disease) and the patient, family, and clinician agree that the treatment is likely to benefit the patient and what the patient would choose. However, some situations are less obvious and not easily resolved, such as a patient with marginal difficulties understanding, appreciating, or reasoning about a health care decision, who is refusing recommended treatment in situations where treatment and treatment refusal carry significant risks. In such situations, objective and transparent procedures for determining capacity are needed.

Assumption #3: Capacity must be studied with a construct validity approach

Capacity is a construct with clinical, ethical, and legal referents and, in this regard, is unique among clinical constructs. Although a clinician’s opinion is currently the accepted standard for capacity determination—there is no “gold” standard—clinical opinion can be inaccurate, unreliable, and invalid. Thus, understanding capacity requires a construct validation approach, where multiple lines of reliability and validity evidence are interwoven to establish knowledge about the nature, workings, and measurement of the construct

Legal Basis of Consent Capacity

Informed Consent

Informed consent for medical treatment has been defined as an autonomous action undertaken by a patient, authorizing a professional to initiate a medical plan for the patient or to withdraw health care, including life sustaining care¹. Modern concepts of informed consent reflect a clinician's dual goals of promotion of patient autonomy and protection of the patient from harm. These goals represent a shift in the approach to healthcare related to three factors: (1) increasing technology, which resulted in the extension of life sometimes at the cost of quality of life, (2) some incidents of physician abuse particularly within medical research, and (3) the patient rights movement of the 1960s and 1970s¹.

Informed consent in contrast to simple consent

Simple consent refers to the physician obtaining the patient's agreement to an intervention or procedure, but without full disclosure of information about the procedure. In contrast, informed consent indicates agreement after the patient has been informed of the risks and other facts of the condition and procedure. Informed consent evolved as a legal requirement following case law in which physicians were held liable for failing to disclose the risks of procedures to patients².

Disclosure

Standards for disclosure include: (a) Nature of procedure or intervention, including its purpose (e.g., diagnostic vs. interventional), duration, where it takes place, use of anesthesia, instruments used, bodily parts affected, and whether it is experimental; (b) Risks, especially those that are material, substantial, probable, significant, as well as the magnitude of the risk, probability, and imminence (when it will happen); (c) Alternatives including the option of no treatment; (d) Benefits, including the limits to the benefits, such as that the procedure is diagnostic not therapeutic or that the procedure may relieve suffering only to a certain degree and not entirely^{1,3}.

Exceptions to Duty to Obtain Informed Consent

There are numerous legal exceptions to the physician's duty to obtain consent, including: (a) Emergencies where there is a need for action to protect against severe bodily harm; (b) when a patient freely and voluntarily waives disclosure and informed consent; (c) when a patient is undergoing court-ordered compulsory treatment; (d) and incapacity (but consent is required from another party). There is also some discussion and limited case law^{1,3} indicating that informed consent may not be required in cases of therapeutic privilege in which disclosure of information would create a substantial adverse impact on the patient's condition.

Statutory Basis of Capacity to Consent

Incapacity as Defined in Surrogate Health Care Decision-Making Statutes

Statutes in every state provide for surrogate health care decision-making for those individuals lacking the capacity to provide informed consent for treatment. Forty-seven states and the District of Columbia have living will laws allowing a person to make a written statement spelling out instructions about treatment or withholding or withdrawing treatment in the event of a terminal or end-stage condition or permanent unconsciousness. All 50 states and the District of Columbia have health care power of attorney statutes (also referred to as medical power of attorney or health care proxy) allowing an individual to appoint an agent to make health care decisions in the event of incapacity. Some state statutes, as well as the Uniform Health-Care Decisions Act⁴, have combined living wills and health care powers of attorney into a comprehensive advance directive act. In addition, over 35 states and the District of Columbia have enacted statutes specifically authorizing default surrogate consent, generally by a hierarchy of family members. The Uniform Health Care Decisions Act also provides for default surrogates⁵.

In all of these statutes, surrogate health care decision-making authority is triggered by a patient's lack of capacity to give informed consent for treatment. The Uniform Health-Care Decisions Act defines capacity as "the ability to understand significant benefits, risks, and alternatives to proposed health care and to make and communicate a health-care decision" (§1(3)). Various state definitions of incapacity under health care power of attorney statutes or living will statutes provide definitions of incapacity similar to the Uniform Act. For example, in Kentucky, capacity is defined as the ability to make and communicate a healthcare decision. In Massachusetts, capacity is defined as the ability to understand and appreciate the nature and consequences of health care decisions, including the benefits and risks of and alternatives to any proposed health care, and to reach an informed decision. In Nebraska, an incapacitated person is defined to have an inability to understand and appreciate the nature and consequences of health care decisions, including the benefits of, risks of, and alternatives to any proposed health care, or the inability to communicate in any manner an informed health care decision. Florida more succinctly defines a patient with incapacity for informed consent for health care as one who is physically or mentally unable to communicate a willful and knowing health care decision. Other states refer to the capacity standard delineated in the adult guardianship law for the state. State by state citations for living will and health care power of attorney statutes can be found on the American Bar Association (ABA) website (<http://www.abanet.org/aging/>).

Incapacity as Defined in Guardianship Statutes

Guardianship is a relationship created by state law in which a court gives one person, the guardian, the duty and power to make personal and/or property decisions for an individual determined by the court to be incapacitated. Guardians are often empowered to make medical decisions on behalf of adults who lack capacity to consent. The Uniform Guardianship and Protective Proceedings Act⁶ defines an incapacitated individual as someone who is unable to receive and evaluate information or make or communicate decisions to such an extent that the individual lacks the ability to meet essential requirements for physical health, safety, or self-care, even with appropriate technological assistance. The 1997 model act adds an emphasis on decision making and de-emphasizes a diagnostic standard. Three states (Colorado, Minnesota,

Hawaii) have statutes based on the 1997 model act, while others are based on an earlier 1982 version; still other states have incapacity standards that are particular to statutory evolution within their state.

A useful analysis of incapacity standards in state guardianship law finds that states may include one or more of the following tests or elements to define incapacity: (a) a disease or disorder; (b) cognitive or decisional impairment; (c) functional disabilities (i.e., “inability to care for self”); and (d) exceeding an essential needs threshold such that there is an unacceptable risk to the person or society^{7,8}. These elements are similar to a proposed general model of incapacity articulated by Grisso⁹, described in the conceptual considerations section below. State by state comparison of incapacity standards for guardianship can be found on the ABA website (<http://www.abanet.org/aging/guardianship.html>).

Limitations on Proxy Authority

Most states limit the authority of guardians and of health care proxies/durable powers of attorney to consent to treatment. Common limitations include the authority to make decisions concerning commitment for mental health treatment, abortion, sterilization, psychotropic medication, amputation, and electro-convulsive therapy¹⁰. Typically, these treatments require review by courts or ethics committees.

Case Law Standards for Capacity to Consent

Five standards for incapacity can be found in case law, used either individually or conjointly as a so-called “compound standard”¹¹⁻¹⁴.

Expressing a Choice. Uncommunicative patients who cannot convey a treatment choice are seen to lack capacity. However, simply evidencing a choice does not, by itself, indicate capacity. While some degree of vacillation or ambivalence is normal, patients must be able to convey a relatively consistent treatment choice.

Understanding. The ability to comprehend diagnostic and treatment-related information has been recognized in many states as fundamental to capacity. Understanding includes the ability to remember and comprehend newly presented words, concepts, and phrases, and to demonstrate that comprehension by paraphrasing diagnostic and treatment information.

Appreciation. 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, is an appreciation standard of capacity². Thus, understanding emphasizes comprehension, while appreciation focuses on evaluation of understood information in terms of personal relevance and beliefs. Disavowal of the diagnosis or potential treatment benefit may signify a deficit in reality-testing (e.g., delusional disorder) or neurological dysfunction (e.g., anosognosia).

Reasoning. Many states have cited the ability to state rational explanations or to process information in a logically or rationally consistent manner, as a key element of capacity. Reasoning has been defined as the ability to evaluate treatment alternatives by integrating,

analyzing, and processing information in order to compare them in light of potential consequences and their likely impact on everyday life.

Rational Choice. A fifth standard encountered in some states, but considered by some commentators to be problematic, is the standard of a reasonable or rational choice. However, it is difficult, if not impossible, to provide an objective standard to the nature of the decision. In subsequent reviews of the literature, we will not discuss empirical findings concerning the making a rational choice, as this has not been the subject of much study. We will also not consider empirical findings concerning evidencing a choice, because this is a threshold ability that has also not been widely studied.

Consistency of Choices with Values

While the four standard model of consent capacity has advanced the field of consent capacity assessment considerably, this model may have diminished a focus on the role of values assessment in consent capacity determination. Various commentators have defined capacity as decisions that adhere to the patient's values, or have suggested that reasoning be operationalized not by basis of logical consistency, but on the basis of consistency with values. The 1982 President's Commission for the study of Ethical Problems in Medicine and Biomedical and Behavioral Research¹⁵ defined capacity in terms of the various cognitive standards previously described (communication, understanding, reasoning, deliberation), but also as "the possession of a set of values and goals." The commission states that a set of values and goals is foundational to the comparison of treatment alternatives.

Similar standards are recognized in language in state statutes for advance directives and guardianship that emphasize autonomy and values. More recently, the American Bar Association's 2002 Model Rules of Professional Conduct (<http://www.abanet.org/cpr/mrpc>), describe factors to be balanced in the determination of capacity to include "the consistency of a decision with the known long-term commitments and values of the client (rule 1.14, comment 6)." These factors are identified in comments to the Model Rule based on recommendations from the National Conference on Ethical Issues in Representing Older Clients and, in particular, a law review article by Margulies¹⁶.

Berg and colleagues¹, in a review of standards for informed consent, conclude that, from an ethical perspective, the standard of capacity that is most justifiable is one that promotes autonomy, protects welfare, and may be employed by practitioners with a minimum of bias, specifically that the "decision maker must first understand and appreciate the risks and benefits of options presented and then weigh those options to make a decision in light of her own values". As such, the assessment of values and the consistency of choices with values is a critical component of capacity evaluation. Such considerations may flow naturally into the forensic evaluation of the reasoning standard, as treatment risks and benefits are weighed in light of personal values. Or, the values component may stand as part of the evaluator's process of capacity judgment, when all sources of data (diagnosis, symptomatology, decisional abilities) are considered in light of the patient's values, attitudes, and perspectives.

Conceptual Basis of Consent Capacity

How does a clinician evaluator integrate standards deriving from case law, proxy consent statutes, and guardianship statutes, in arriving at a useful conceptual model of capacity for clinical practice? While evaluators are encouraged to formulate a model specific to their jurisdictional standards, an integrative model that synthesizes case and statutory models, including values, can be helpful.

An Integrative Conceptual Model for Consent Capacity

Grisso (2003) provides a starting point for such an integrative model. The five components of the Grisso model are described below vis-à-vis consent capacity. A key point is that an assessment of consent capacity does not rest on only the assessment of decisional abilities, but also the etiology and related symptoms as interpreted in context.

Causal Component

The causal component refers to the etiology or reason behind any observed decision making difficulties. In addition to explaining why decision making is affected, information about the cause explains whether the observed deficits may be permanent or temporary. For example, consent impairments associated with Alzheimer's disease would be permanent and progressive, whereas consent impairments associated with acute confusional states or depression would be expected to improve with treatment of the underlying condition.

Functional Component

For the purposes of consent capacity, the functional component refers to the decision making abilities, as well as general cognitive abilities (memory, language, thought processes). In terms of assessment, the functional component is assessed by specific, direct questioning (using interview or standardized instruments) of key abilities relevant to consent capacity as well as more general symptomatic assessment of the presence, severity, and frequency of cognitive or psychiatric symptomatology.

Interactive Component

The interactive component recognizes that the above sources of information must be considered in view of the particulars of the situation, including the complexity of the treatment decision, the severity of risk associated with treatment outcomes, and the individual's long held values, preferences, and patterns.

Judgmental Component

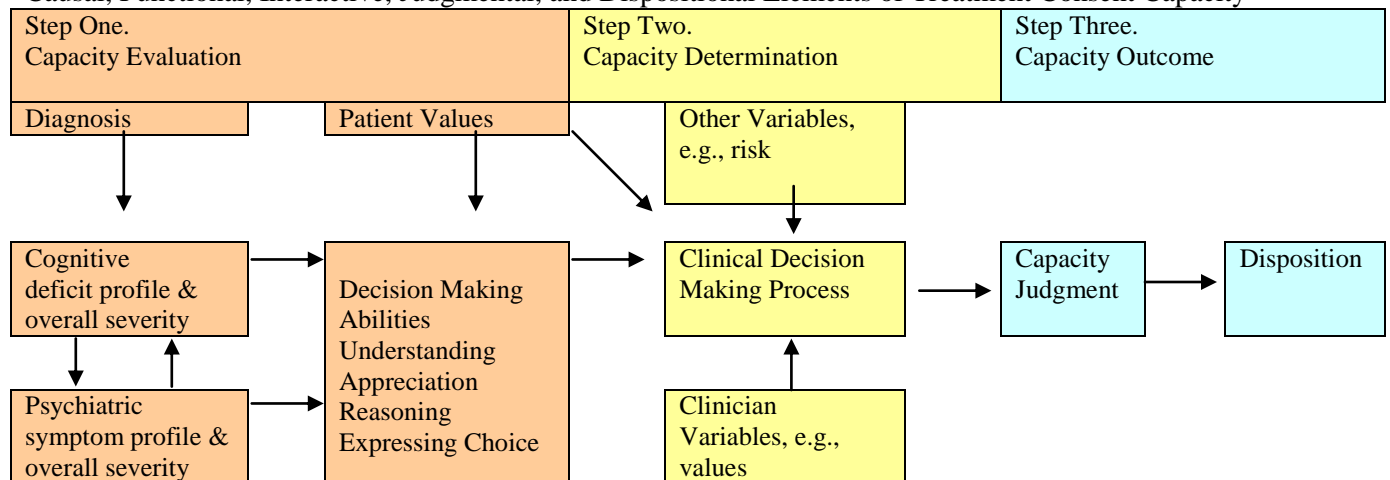
The judgmental component of capacity recognizes that capacity determination is a professional clinical or legal judgment wherein the various components are weighed to arrive at an outcome

regarding the patient's capacity. While capacity may, in fact, be a continuous variable, with some individuals having marginally impaired decision making for some decisions, for any specific informed consent situation a dichotomous (yes/no) decision must be rendered regarding the individual's capacity. It is not clear how clinicians or judges weigh various components, but it has been observed that a clinician's judgment may be influenced by a range of factors, including their experience in the field¹⁷, professional discipline¹⁸, the weight that is given to particular cognitive deficits¹⁹, and competing goals and perspectives of clinicians and patients²⁰.

Dispositional Component

Any specific capacity determination will result in an outcome that may include the use of substituted judgment by a previously appointed proxy, guardian, or next of kin (for a thorough consideration of substituted judgment, see²¹). It is also possible that the disposition may include recommendations to treat underlying causes of incapacity, or to use information processing aids (e.g., lists, diagrams, reminders) to maximize decisional abilities in patients with marginal capacity.

Causal, Functional, Interactive, Judgmental, and Dispositional Elements of Treatment Consent Capacity



Step One shows the range of patient variables that may be evaluated. Clinicians vary in whether they consider each of these variables and, importantly, how they assess each variable.

Step Two illustrates the complexity of the capacity determination process. Clinicians weigh the importance of each variable according to a variety of factors, including their own values and the degree of risk in the situation, to arrive at a capacity judgment. In this step, the "Clinical Decision Making Process" box is akin to the proverbial "black box"—that is, we see the externally visible behavior (the clinical judgment), but we do not yet know which variables clinicians emphasize and the decision making process leading to the clinical judgment.

Step Three describes the outcome of a capacity determination process. A dichotomous (yes/no) opinion is made and presupposes a disposition for the patient; either the patient will make the decision (even if others disagree) or a surrogate decision maker will render a decision for the patient (even if the patient disagrees).

Additional Considerations

Situation Specificity

The assessment of consent capacity is situation specific. That is, an individual's capacity may vary depending on the difficulty and complexity of a medical decision. An individual with neurocognitive compromise may have diminished capacity to consent to a complex medical intervention but may retain the capacity to consent to a relatively simple medical treatment. As such, consent capacity must be evaluated for each specific informed consent situation. However, in practice, particularly in activation of proxy authority, families and clinicians may find it useful to know whether an individual has the capacity to make a current treatment decision and subsequent decisions of similar complexity. Similarly, in writing guardianship orders, especially if crafting a limited order, a judge may want information relative to an individual's capacities within key decisional domains, so that the judge can articulate those decisions for which the patient retains decisional autonomy and authority.

Disclosing Treatment Information

Clinicians are obligated to disclose information about the nature of the procedure, risks, benefits, and treatment alternatives. However, little is written about how information disclosure may impact the latter assessment of consent capacity. Disclosure formats that are more structured, organized, uniform, and brief serve to improve understanding of diagnostic and treatment information, as do simplified and illustrated guides²². Not surprisingly, informed consent performance was improved when consent forms were left available for subsequent reference²³. These findings are supported by cognitive aging research that finds environmental aids (e.g., cues for the retrieval of relevant information) reduce demands on cognitive resources subserving working memory. In contrast, tasks that require effortful processing without such supports are more likely to reveal age-related impaired performance²⁴⁻²⁶.

Framing

Furthermore, decisions are influenced by the manner in which risks are framed. McNeil and colleagues²⁷ showed that participants who learned that 10% of patients die from surgery and 0% die from radiation were less likely to choose surgery compared to those who were presented with information that 100% of patients immediately survive radiation and 90% immediately survive surgery. Thus, participants are most likely to choose the more positively framed outcome, despite identical outcome probabilities. This effect has been demonstrated in a wide range of populations²⁸, including older adults asked to make medical decisions regarding life-threatening²⁹ and less threatening outcomes³⁰.

Simplification and Cognitive Processing

Evaluators are obligated to present information in such a way as to maximize understanding in light of an individual's level of education, language ability, and medical sophistication. If simplification of information presented is acceptable, in fact necessary, at what point does simplification become a failure to disclose sufficient information? Similarly, how much information must a patient comprehend in order to demonstrate adequate understanding? Normative studies of consent comprehension provide some guidance³¹, and interestingly reveal that healthy, unimpaired adults remember and comprehend far less information than may be assumed. Further, it remains unclear to what extent understanding forms the basis for

subsequent appreciation and reasoning. If an individual cannot attend to, encode, and comprehend basic information about a treatment, to what extent can he or she be expected to appreciate its significance or reason about related risks and benefits? While one study suggests that understanding, appreciation, and reasoning do not form a hierarchical model³², such investigations are dependent upon cut-off scores used for adequate comprehension.

Lifespan developmental studies of cognitive processing in adults indicate that implicit cognitive processing is utilized in arriving at decisions and that, as adults age, they may consider fewer pieces of information in arriving at decisions. Some have framed these findings as age-related decrements in working memory³³, while others emphasize that rapid focusing upon personally salient information may be a benefit of life experience, such that individuals become more expert in decision making with more experience³⁴. If so, assessments of understanding and subsequent appreciation and reasoning that emphasize a necessary amount of information recall or comprehension may be unfair.

In summary, there are limitations to the maxim that consent capacity is “situation specific.” Doctors, families, and judges may need to know an individual’s decisional capacities for decisions of similar complexity. However, decisional complexity may be reduced, to a limited extent, by simplification either in the way that the clinician chooses to disclose the information or in the way that the patient chooses to focus on and sort key information. The limits of simplification remain an empirical question: When does clinician simplification lead to a failure of adequate disclosure and when does patient simplification result in inability to adequately weigh essential information?

Chapter 2. Existing Measures and Empirical Findings

Instruments

A major empirical advance in the past ten years has been the development of forensic assessment instruments and interview guides for evaluating capacity to consent to medical treatment. These instruments use either a standardized vignette or provide a structured format and questions to use for an actual treatment situation. A standardized vignette is useful if the clinician believes it would be illuminating to assess a patient's decisional abilities in a treatment context separate from the one facing a patient. Also, a vignette paradigm could be necessary if there is not a specific medical decision facing the patient but, instead, the evaluator is being asked to comment more generally on likely consent capacity in a future decisional context (e.g., for the purposes of guardianship). In other cases, it will be helpful to use an instrument that can be tailored to a current consent situation.

Although currently available instruments show some promise, they should be used with an awareness of the limitations of each instrument, and with the knowledge that a score on an instrument is not intended to supplant clinical judgment. Instruments are useful in that they provide examples of how to conceptualize and operationalize the aforementioned decisional abilities. In selecting instruments for use as resources, it seems most prudent to select tests developed for the population being assessed (i.e., schizophrenia versus dementia). In some cases, instruments may be selected based on the appropriateness of the content (e.g., the Competency Interview Schedule (CIS) when assessing capacity to consent to ECT).

Vignette-based Instruments

Capacity to Consent to Treatment Instrument (CCTI) ³⁵

The CCTI is based on two clinical vignettes, a neoplasm condition and a cardiac condition. Vignettes are presented orally and in writing; participants are then presented questions to assess their decisional abilities in terms of understanding, appreciation, reasoning, and expression of choice. Responses are subjected to detailed scoring criteria.

Competency Interview Schedule (CIS) ³⁶

The CIS is a 15-item interview designed to assess consent capacity for electro-convulsive therapy (ECT). Patients referred for ECT receive information about their diagnosis and treatment alternatives by the treating clinician, and the CIS is used to assess decisional abilities based on responses to the 15 items.

Decision Assessment Measure (DAM) ³⁷

Wong and colleagues, working in England, developed a measure that references incapacity criteria in England and Wales (retention, understanding, reasoning, and communicating a choice). A standardized vignette regarding blood drawing is used.

Hopemont Capacity Assessment Interview (HCAI) ³⁸

The HCAI medical decision-making component consists of 2 clinical vignettes, treatment of an eye infection and administration of cardio-pulmonary resuscitation (there are also two vignettes to assess financial capacity). The patient is introduced to general concepts of choice, risk, and benefit, followed by the two scenarios. After discussing the scenarios, patients are asked to recount factual information, explain risks and benefits, state a decision, and explain how the decision was reached.

Thinking Rationally about Treatment (TRAT) ³⁹

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

Understanding Treatment Disclosures (UTD) ⁴⁰.

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

Additional Vignette Assessment Methods

A few studies do not use specifically named instruments, but are based on standardized vignettes and questions that presumably could be replicated by other investigators. Research by Schmand et al. ⁴¹ uses a vignette based on work by Sachs et al. ⁴² that describes physical therapy or surgery for a hip fracture. Nine questions approximate an assessment of the four decisional abilities. There is also a standardized vignette for consent to a medication research trial.

Fitten and colleagues (Fitten, Lusky, & Hamann, 1990; Fitten & Waite, 1990) employ three standardized vignettes: treatment for insomnia, a procedure for diagnosis of pleural effusion, and resuscitation in the context of chronic illness. Follow-up questions address the patient's

understanding of the condition, the nature and purpose of the proposed treatments and their risks and benefits, and the “quality” of the patient’s reasoning process.

Structured or Semi-Structured Interviews

Aid to Capacity Evaluation (ACE) (Etchells, et al., 1999)

The ACE is a semi-structured assessment interview that addresses seven facets of capacity for an actual medical decision: the ability to understand (a) the medical problem; (b) the treatment; (c) the alternatives to treatment; (d) the option of refusing treatment; (e) the ability to perceive consequences of accepting treatment; (f) refusing treatment; and, (g) the ability to make a decision not substantially based on hallucinations, delusions, or depression. These reflect legal standards in Ontario, Canada but also correspond to U.S. legal standards. Questions in the areas a-d assess the decisional ability of understanding. Questions in areas e and f appear to tap reasoning, and in area g diminished appreciation based on patently false beliefs (e.g., “Do you think we are trying to harm you?”).

Capacity Assessment Tool (CAT) ⁴³

The CAT proposes to evaluate capacity based on six abilities: (a) communication; (b) understanding choices; (c) comprehension of risks and benefits; (d) insight; (e) decision/choice process; and, (f) judgment. It uses a structured interview format to assess capacity to choose between two options in an actual treatment situation.

MacCarthur Competence Assessment Tool - Treatment (MacCAT-T) ⁴⁴

The MacCAT-T utilizes a semi-structured interview to guide the clinician through an assessment of understanding, appreciation, reasoning, and expressing a choice. Appreciation is assessed in two sections: whether there is “any reason to doubt” the diagnosis, and whether the treatment “might be of benefit to you.” Reasoning is assessed through questions considering how patients compare treatment choices and consequences and apply treatment choices to everyday situations. Perceptions of Disorder (POD) ⁴⁵. The POD is one instrument developed along with the TRAT and UTD, which are precursors to the MacCAT-T. The first part, Non-Acknowledgement of Disorder, presents facts of the patient’s actual disorder and then asks the patient to rate agreement with those facts as applying to oneself. The second part, Non-Acknowledgement of Treatment Potential, elicits opinions about whether treatment in general, and medication in particular, might be of some benefit. Low ratings are given when disbelief is based on grossly distorted or delusional premises.

Capacity Research

Review of Current Research Findings

Relation of Capacity Instruments to Neuropsychological Tests

Understanding

Several studies have considered the relation of the four decisional abilities to neuropsychological measures using univariate correlation or multivariate regression, generally in older samples. In 29 older adults with Alzheimer's disease (AD) (Marson, Chatterjee, Ingram, & Harrell, 1996), understanding (on CCTI) was best predicted by the Dementia Rating Scale (DRS) conceptualization and confrontation naming ($R^2=.70$). Another study (Dymek, Atchison, Harrell, & Marson, 2001) with 20 older adults with Parkinson's disease (PD) found understanding (CCTI) was predicted by performance on an executive battery and DRS memory ($R^2=.68$). Generative naming and confrontation naming showed the strongest correlations with understanding (MacCAT-T) in 20 long term care older adults with multiple comorbidities (Moye & Karel, 1999). In 43 acutely hospitalized adults, understanding (UTD) was correlated ($r = .45$) with a linear composite of verbal cognitive functioning that combined scores on WAIS vocabulary, similarities, and digit span (Frank, Smyer, Grisso, & Applebaum, 1999). Understanding (UTD) also correlated ($r = .34-.36$) with a similar linear composite of verbal cognitive functioning in 92 adults with depression (M age 35) and, to a lesser extent ($r = .12-.33$), in 75 adults with schizophrenia (M age 34) (Grisso & Appelbaum, 1995b).

Appreciation

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

Reasoning

In these same studies, CCTI reasoning (indexed as the total number of rational reasons provided) was best predicted by verbal fluency and DRS initiation/perseveration in older adults with AD and controls ($R^2=.36$) (Marson, Cody, Ingram, & Harrell, 1995) and by an executive battery in older adults with PD ($R^2=.45$) (Dymek et al., 2001). Univariate analyses found correlations between reasoning on the MacCAT-T (a series of questions comparing and contrasting reasons for choice including generating everyday consequences of treatment alternatives) and working memory (digits backward) in long term care residents (Moye & Karel, 1999), and between

TRAT reasoning and a WAIS verbal composite in adults with schizophrenia ($r = .37-.39$) and depression ($r = .27-.30$) (Grisso & Appelbaum, 1995b). WAIS verbal performance was not significantly correlated with reasoning in adults undergoing acute medical hospitalization (Frank et al., 1999).

Expressing a Choice

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

Expressed as a global score, capacity correlates most highly with language expression, language comprehension, and abstract thinking (Schmand et al., 1999). In another study where capacity was considered as a total score (on the HCAI), immediate memory best predicted capacity ($R^2=.27$) (Staats, Edelstein, & Null, 1995).

Relation of Capacity Instruments to Cognitive Screening Tests

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

Relation of Capacity Instruments to Non-Cognitive Variables

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

Relation of Two or More Capacity Instruments

Relation of Capacity Instruments to Clinical Judgment

Studies comparing test-based and clinician-based evaluations of capacity typically employ threshold instrument scores and categorical (intact capacity/impaired capacity) clinical judgments. Fitten and Waite (1990) found poor agreement between an instrument-based assessment emphasizing recall and physician-based determinations in 25 acutely ill hospitalized elderly adults. Physician-based and instrument-based ratings disagreed in 28% of the patients, and physicians were more likely than the instrument to rate patients as having intact capacity. Similar results were found in long term care residents (Fitten et al, 1990; Bean et al, 1996).

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

Group Differences

Schizophrenia

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

Dementia

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

impaired on understanding (CCTI, HCAI, MacCAT-T), appreciation (CCTI only), and reasoning (CCTI and MacCAT-T) in mean comparisons with controls (Moye, et al., 2004).

Categorical comparisons using norm-based cut-offs for the CCTI found that 33% of patients with mild AD scored in an impaired range (> 2 standard deviations below normative mean) on appreciation, 53% on rational reasons, 100% on understanding, and 13% on evidencing a choice (Marson, Ingram, et al., 1995). Rates were higher for adults with moderate AD. Marson et al. (1999) noted that loss of task (difficulty projecting oneself into the story), non-responsive answers, and loss of detachment (confusion over the hypothetical nature of the task) characterize capacity impairment in dementia.

Institutionalized or Hospitalized

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

Test-Retest Reliability

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

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

Reliability between Clinicians

There are few empirical studies of the inter-rater reliability of clinical capacity assessment. Marson et al. (1997) found low agreement ($\kappa = .14$) between five physicians with different specialty training who provided dichotomous capacity ratings of adults with AD based on the videotaped administration of instrument-based assessments (MMSE and CCTI). Agreement improved when physicians were trained to evaluate specific legal standards ($\kappa = .48$), but there was still considerable variability (Marson, Earnst, Jamil, Bartolucci, & Harell, 2000). Physicians appear to inconsistently weight different cognitive abilities in capacity assessments, emphasizing either naming, conceptualization, or memory (Earnst, Marson, & Harrell, 2000). Moreover, ratings may vary by specialty (psychiatry, neurology, and geriatrics) (Marson, McInturff, et al., 1997). Cognitive impairment may influence clinicians' assessments of capacity differently, depending on the clinician's personal rating style (Marson, Hawkins, McInturff, & Harrell, 1997). Another potential source of evaluator bias lies in the observation that incapacity may be more frequently diagnosed in treatment-refusers than in treatment-acceptors (Bean, Nishisato, Rector, & Glancey, 1996).

Normative Properties

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

Table 2.1. Healthy Control Group Samples on Consent Capacity Instruments

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

^aValues range because subjects were aged matched to one of three patient groups.

^bStudy describes consent capacity as measured by standardized vignette, although no instrument name is provided.

^cNo education level provided, but socio-economic status (education + occupation) is given.

*No information available.

Review of Moye et al. Findings

In a study funded by NIMH from 1999-2004, 88 older adults with dementia and 88 controls completed three instruments for assessing consent capacity (CCTI³⁵, HCAI³⁸, MacCAT-T⁴⁴) and a neuropsychological battery. Re-testing occurred at 9 and 18 months. A series of studies examined four questions regarding the construct validity of consent capacity as currently measured and led to a set of needs to be addressed in developing the ACCT.

Study 1: Content Validity of Understanding, Appreciation, Reasoning, and Expressing a Choice

Across the three instruments, the abilities of Understanding and Expressing a Choice were operationalized similarly, and demonstrated high convergent validity in multi-trait multi-method comparisons. In contrast, Appreciation was operationalized as either distrust or lack of foresight, and demonstrated low convergent validity across instruments. Reasoning was operationalized as provision of rational reasons on two measures, and as comparative and consequential reasoning on the third measure, with low convergent validity⁴⁶.

Table 2.2. MTMM Matrix.

		MacCAT-T				HCAI				CCTI			
		Under	Appr	Reas	Choice	Under	Appr	Reas	Choice	Under	Appr	Reas	Choice
MacCAT-T	U	.77											
	A	.42*	.19										
	R	.48*	.34*	.42									
	C	-.03	.04	.24	+								
HCAI	U	.77*	.47*	.47*	.02	.74							
	A	.42*	.20	.31*	.00	.42*	+						
	R	.57*	.36	.42*	.02	.74*	.23	.59					
	C	.51*	.50*	.43*	-.07	.64*	.27	.53*	.03				
CCTI	U	.74*	.39*	.46*	-.02	.74*	.37*	.56*	.56*	.87			
	A	.24	.15	.15	-.04	.23	.19	.13	.18	.26	.49		
	R	.31*	.35*	.26	.01	.39*	.04	.40*	.37*	.50*	.28*	.39	
	C	.13	.19	.27	.25	.29*	.14	.21	.30*	.14	-.01	.20	.32

Note. Outline: Mono-trait Hetero-method (MTHM); Shaded: Hetero-trait Mono-method (HTMM); Bold: Hetero-trait Hetero-method (HTHM); Italics: Mono-trait Mono-method (internal consistency/alpha).
 *p < .01 level, Pearson Correlation, 2-tailed. + Alpha cannot be computed as there is only one item.

In summary, the three instruments were developed to assess capacity in different populations (CCTI³⁵-dementia, HCAI³⁸-long term care, MacCAT-T⁴⁴-psychiatric) and approaches were not always relevant to patients with dementia. Across instruments, there was consistency and good convergent validity for assessing Understanding and Expressing a Choice, and inconsistency and low validity for assessing Appreciation and Reasoning. More work is needed to establish how to assess these abilities in different clinical populations.

Study 2: Differences in Dementia and Controls

Adults with dementia performed worse than controls on all measures of Understanding. Adults with dementia were impaired on Appreciation when measured as foresight but not when measured as distrust. Adults with dementia performed worse on Reasoning when assessed as a comparison of risks and benefits and as a listing of all rational reasons. Almost all participants in both groups were able to express a treatment choice⁴⁷.

Table 2.3. Mean Differences in Decisional Abilities Between Adults with Dementia Versus Controls

Ability	# items	range	Control		Dementia		F	df
			M	SD	M	SD		
Understanding								
MacCAT-T	12	0-24	18.84	3.03	16.92	4.17	7.13*	4,162
HCAI	14	0-28	25.49	1.86	24.19	3.38	5.34*	4,171
CCTI	18	0-130	55.61	8.33	45.99	13.98	26.44*	4,170
Appreciation								
MacCAT-T	2	0-4	3.78	0.57	3.79	0.54	0.18	4,162
HCAI	1	0-2	1.77	0.47	1.66	0.52	1.93	4,173
CCTI	2	0-8	6.20	1.34	4.98	1.60	11.03*	4,169
Reasoning								
MacCAT-T	4	0-8	7.28	0.95	6.67	1.32	7.83*	4,162
HCAI	3	0-6	4.95	1.33	5.07	1.29	0.66	4,171
CCTI	2	0-20	5.02	2.00	3.91	1.92	11.84*	4,174
Expressing a Choice								
MacCAT-T	1	0-2	1.97	0.23	1.96	0.19	0.06	4,162
HCAI	3	0-6	5.88	0.37	5.79	0.56	1.01	4,171
CCTI	2	0-4	3.98	0.21	3.94	0.32	0.70	4,170

* $p < .01$, ANCOVA F for group effect controlling for age, education, and gender.

In summary, group comparisons found that measures of Understanding, Reasoning, and Appreciation as foresight are relevant for capacity consent assessment in dementia, but Appreciation as distrust is not.

Study 3: Neurocognitive Predictors of Decisional Abilities

Three neuropsychological factors were determined through factor analysis⁴⁸.

- Factor 1. Verbal Retrieval:** Logical Memory I (.916), Logical Memory II (.935), and Boston Naming (.560)
- Factor 2. Problem Solving:** Trails A (.812), Trails B (.736), Mazes (.801), and Visual Search/Attention (.629)
- Factor 3. Initiation & Knowledge:** Digits Forward/Backward (.836), FAS (.804), Vocabulary (.676).

These three factors were differentially predictive of decisional abilities in multiple regression:

Table 2.4 Factor Loadings of Decisional Abilities on Neuropsychological Factors

Ability	R2	β Factor 1	β Factor 2	β Factor 3	p
Understanding	.78	.75	.29	.35	.01
Appreciation	.25	.34	.28	.23	.02
Reasoning	.40	.45	.34	.28	.01
Expressing choice	.10	.23	.00	.22	.03

In summary, Understanding was most highly predicted by neuropsychological tests, namely Verbal Retrieval, suggesting good criterion-related validity for this ability. However, Understanding may rely too strongly on verbal memory. Appreciation and Reasoning demonstrated lower criterion-related validity with neuropsychological tests, and had loadings split across the neuropsychological factors.

Study 4: Performance over Time

Subjects were rated as impaired or unimpaired based on cut-off scores of 2.5 SD below the normal mean⁴⁹. In the dementia group, 9.4 % had impaired capacity initially, and 26.4% had impaired capacity at nine months. Mean scores in the dementia group were impaired relative to controls initially and at 9 months for Understanding (initial $t=2.49$, $p=.01$; 9 month $t=3.22$, $p<.01$) and Reasoning (initial $t=2.18$, $p=.03$; 9 month $t=4.77$, $p<.01$). Declining capacity over 9 months was attributable to a further reduction in Reasoning (group x time $F=8.19$, $p=.005$). Discriminant function analysis revealed that initial scores on Naming, delayed Logical Memory, and Trails B were associated with impaired capacity at nine months.

Table 2.5. Mean Values for Decisional Abilities in Adults with Dementia Versus Controls over 9 months

Ability	Control M (n = 59)		Dementia M (n = 59)		Group F	Time F	Group x Time F
	Initial	9 mos.	Initial	9 mos.			
Understanding	18.75	19.51	17.17	17.15	9.74*	1.99	2.19
Appreciation	3.76	3.88	3.79	3.76	0.39	1.44	0.48
Reasoning	7.31	7.20	6.81	5.93	22.49*	10.47	6.60*
Choice	2.00	1.96	1.94	1.96	1.33	0.78	0.33

* $p < .01$

In summary, some patients with mild to moderate dementia developed a clinically relevant impairment of consent capacity within a year, associated with declining Reasoning. Interventions that maximize Understanding and Reasoning by supporting naming, memory, and flexibility may help to optimize capacity.

Study 5: Agreement of Instruments

The kappa for overall capacity was .451 ($\kappa = 150.32$, $df = 78$, $p < .001$), indicating only fair 3-way agreement beyond chance⁵⁰. Kappa for understanding was .618 ($\kappa = 176.70$, $df = 78$, $p < .001$), indicating very good agreement across all instruments. Kappa for expression of choice differed

significantly from zero (.158, $\kappa = 104.01$, $df = 78$, $p = .026$), but kappas for appreciation (-.039) and reasoning (.047) did not.

Table 2.6 provides pairwise rating frequencies and (on the right) corresponding kappas. Note that MacCAT-T and HCAI demonstrated excellent agreement beyond chance for understanding ($\kappa = .802$), and good agreement for capacity (.607), whereas CCTI showed only fair pairwise agreement for these variables (κ range = .400-.580). MacCAT-T and HCAI showed poor agreement for reasoning, and MacCAT-T and CCTI showed poor agreement for expression of choice; all other pairwise comparisons demonstrated chance agreement. Compared to MacCAT-T and HCAI, CCTI rated more subjects impaired on understanding (13 vs. 8 and 9), appreciation (4 vs. 3 and 2), and choice (9 vs. 3 and 6).

Table 2.6. Pairwise Tabulations and Kappa Coefficients for Capacity Instruments

	Pairwise Tabulations								Kappa	
	CCTI				HCAI				CCTI	HCAI
Ratings ¹	1/1	0/0	1/0	%	1/1	0/0	1/0	%		
Understanding										
HCAI	64	7	8	10.1					.5802	
MacCAT-T	64	6	9	11.4	69	7	3	3.8	.510**	.802**
Appreciation										
HCAI	73	0	6	7.6					-.035	
MacCAT-T	72	0	7	8.9	74	0	5	6.3	-.045	-.031
Reasoning										
HCAI	75	0	4	5.1					-.026	
MacCAT-T	70	0	9	11.4	71	1	7	8.9	-.041	.1903
Expression of Choice										
HCAI	66	2	11	13.9					.193	
MacCAT-T	69	2	8	10.1	70	0	9	11.4	.293††	-.053
Global Capacity										
HCAI	53	9	17	21.5					.400**	
MacCAT-T	52	10	17	21.5	63	8	8	10.1	.416**	.607**

¹ CCTI= Capacity to Consent to Treatment Interview; HCAI= Hopemont Capacity Assessment Interview; MacCAT-T= MacCarthur Competence Assessment Tool – Treatment. 1= intact capacity, 0= impaired capacity. Ratings of ‘1/1’ and ‘0/0’ indicate agreement between instruments regarding presence or absence of intact capacity, whereas ratings of ‘1/0’ indicate disagreement. Percentage of subjects rated differently for each instrument pairing is provided immediately to the right of the corresponding tabulations.

Study 6: Values for Medical Decision Making

To explore the potential role of values in healthcare decisions, a core set of values was identified through literature review including quality of life, desire for input from doctors or family, and concern for others in decision making. A sub-sample rated the extent to which various concerns would influence medical treatment decisions.

Table 2.7 Valued Activities and Abilities

Item	N	Influence A lot (%)	Influence A little (%)	Influence Not at all (%)
My level of physical pain at the moment	95	45.3	27.4	27.4
The level of physical pain involved in the treatment	94	37.2	40.4	22.3
My quality of life at the time	96	62.5	22.9	14.6
Ability to enjoy simply pleasures (read, tv, radio) at the time	97	52.6	22.7	24.7
A desire to live as long as possible	95	47.4	22.1	30.5
The extent to which I would depend on others for personal care	96	58.3	26.0	15.6
Who (family members or professionals) provides personal care	95	58.9	28.4	12.6
The financial impact on my family	94	59.6	16.0	24.5
The emotional impact on my family	91	70.3	19.8	9.9
My feelings and beliefs (e.g., fears) about dying	95	35.8	23.2	41.1
My religious beliefs about the situation	95	34.7	17.9	47.4
Ability to still communicate with others	96	77.1	12.5	10.4
Ability to still make decisions for myself	97	80.4	11.3	8.2

Adults with and without dementia appeared equally able to respond meaningfully to questions about values regarding quality of life and health care decisions. People with dementia were generally as able as controls to respond consistently after nine months. Four values factors on rating scale items were identified through factor analysis: extent of concern for maintaining self-sufficiency; extent of concern about pain and quality of life; extent of concern about preserving life; extent of concern about impact of decisions on the family. The four most highly rated specific values influencing treatment choices were: the ability to still make decisions for myself, the ability to still communicate with others, the emotional impact on my family, and my quality of life at the time.

In summary, adults with and without cognitive impairment were able to describe key values influencing healthcare choices, with relative consistency over time. As such, it should be possible to assess the consistency of choices with values as one indicator of consent capacity.

Study 7: Pilot Study of Cued Procedure in Understanding

Adults with dementia (N=25) and controls (N=25) were provided treatment vignettes using cued (a bulleted list) and un-cued procedures. Performance was then correlated with story recall.

Table 2.8 Mean differences between dementia and control groups using cued and uncued disclosure

Ability	Control M (n = 25)		Dementia M (n = 26)		Group T	Disclosure t
	Standard	Cued	Standard	Cued		
Understanding	28.33	47.44	24.52	40.52	7.05*	168.42*
Appreciation	2.60	2.04	2.32	2.32	0.00	2.76
Reasoning	2.92	3.52	2.60	3.89	0.00	10.65*
Choice	1.92	1.92	1.92	2.00	0.42	0.39

Table 2.9 Association of understanding using cued and uncued disclosure and story recall

Measure	Control r		Dementia r		
	Standard	Cued	Standard	Cued	
Logical Memory I	.51**	-.15	.78**	.55*	*p<.05
Logical Memory II	.48	-.25	.77	.52	

In summary, the use of a visually cued presentation of diagnostic and treatment information maintains meaningful differences between adults with dementia versus controls on Understanding. Using visual cues eliminates or reduces memory demands, enhancing the extent to which the assessment of Understanding focuses on capacity for comprehension versus simple verbal recall ability.

Study 8: Pilot Study Regarding Processing and Reasoning

To evaluate how adults may focus upon and use information during medical decision making, a subsample was asked to rate the importance of various treatment facts in their decision making, after the decision was made.

Total importance ratings (0=not, 1=some, 2=very) varied considerably among participants from 4-17 (M =11.24, SD=3.30), with some participants rating many items as very important, and others selecting only a few items as very important to their decision. Participants who rated more items as very important were more likely to receive higher scores on CCTI reasoning (r = .25).

Participants vary in whether they tend to rate few or many treatment facts as important to their decisions. Individuals who are high in information seeking consider many treatment facts important in their decision making, score higher on CCTI reasoning which measures reasoning as “rational reasons” -- giving credit for the total number of reasons cited. This approach may unfairly penalize individuals who make valid decisions but focus on fewer treatment facts as important in their ultimate decision. The rating and use of treatment information facts, and its relationship to measured “reasoning,” deserves further study.

Summary of Previous Studies

- Diminished capacity is a common concern in older adults with dementia or schizophrenia^{35, 51, 52}.
- Clinical judgments of consent capacity can be inaccurate, unreliable, and invalid^{18, 53, 54}.
- Low reliability and validity presents a considerable ethical concern. Patients judged to be incapable can lose the right to decide the course of their treatment and lives. Conversely, patients who are incapable may be judged capable and thus may accept treatment without understanding the risks^{2, 55}.
- Four abilities—Understanding, Appreciation, Reasoning, and Expressing a Choice—form the legal basis for consent capacity^{11, 56}.
- In both objective rating instruments and clinical judgment, there is good agreement on the measurement of Understanding and Expressing a Choice, although current methods of assessing Understanding have disproportionately high verbal recall demands^{46, 53, 57}.
- In both objective rating instruments and clinical judgment, there is poorer agreement on the measurement of Appreciation and Reasoning. Moreover, measurement strategies developed to assess Appreciation and Reasoning in dementia may work less well in schizophrenia, and vice versa⁴⁶.
- The logical consistency of a patient's treatment choices with his/her values may be a useful indicator of capacity but has not been studied^{1, 15, 16}.

Integration of Findings

Understanding

Summary. In our studies and others, measures of understanding had good content validity (per MTMM Campbell-Fiske Criteria) and criterion validity (associated with immediate memory and vocabulary), were impaired in adults with dementia relative to controls, but did not show declines over 9 months.

Conclusion. There is good agreement on how to measure the capacity of understanding, although the CCTI method may over-emphasize memory per se versus understanding or comprehension. A pilot study of disclosure procedures suggests that information should be disclosed in bulleted lists and left out for future reference.

Appreciation

Summary. Measures of appreciation had poor content and criterion validity (negligible R^2 , low and inconsistent neuropsychological correlates, poor convergence in MTMM), were impaired in the dementia group only on CCTI, and did not show declines over 9 months.

Conclusion. There is not agreement on how the concept of appreciation should be operationalized, whether it is relevant to dementia populations, and what cognitive or psychiatric impairments are most associated with diminished appreciation. The neuropsychological measures used in this study were not predictive of Appreciation. Appreciation as planning and projection (CCTI) may be most relevant for dementia populations. Appreciation as doubt and mistrust (MacCAT-T, HCAI) may be relevant for psychiatric populations.

Reasoning

Summary. Measures of reasoning had fair and variable content and criterion validity (mixed convergence in MTMM, low R^2 , associated with memory, attention, and on the MacCAT-T, mental flexibility), were impaired in adults with dementia compared to controls (on MacCAT-T and CCTI), and showed 9 month declines on the MacCAT-T. Most participants cited a modest number of reasons in justifying their decisions. A pilot study of values suggest that specifically held values may influence decision making in ways not yet capture in traditional capacity instruments.

Conclusion. There are different approaches to measuring reasoning: comparative/consequential (MacCAT-T) and rational reasons (CCTI (all reasons), HCAI (1 risk, 1 benefit)). The comparative/consequential approach is promising although some subjects had trouble detailing the specific ways in which treatments would influence valued life activities and valued others. The rational reasons approach of the CCTI, emphasizing total number of rational reasons, is problematic in that it raises the question “how many reasons is enough”. One subject gave one reason, and when we pressed for more, said “that is enough”. Giving high credit to decision makers who tend to consider all information and low credit to decision makers who focus on one

or two salient factors for their own lives in making decisions, may inaccurately reflect valid reasoning. A pilot study of information processing confirms that some individuals focus on many reasons while others find only a few as important to their decision making.

Expressing a Choice

Summary. Measures of expressing a choice had fair to good content and criterion validity (associated with naming), were not impaired in adults with mild to moderate dementia relative to controls, and did not decline over 9 months. Both groups scored near ceiling.

Conclusion. The ability to express a simple choice appears relatively straightforward to assess and is not likely to be impaired until more advanced stages of illness. Adults who are impaired on simple Expression of choice, will likely not have the ability to understand, appreciate, or reason through information.

Chapter 3. Development of the ACCT-T

Development of the ACCT Interview

The ACCT was developed based on a review of existing instruments⁵⁸, especially the work of Marson and colleagues³⁵, Edelstein and colleagues⁵⁹, and Grisso and Applebaum² and our empirical comparison of their consent capacity instruments^{46,47}. The instrument is provided in Appendix A.

Applications of the ACCT

The ACCT was developed for a research study, but can be adapted to clinical use. For research, a hypothetical vignette is used to elicit treatment choices for an imaginary condition. Standardized scoring using a detailed scoring manual is possible. The psychometric data presented in this manual are based on the use of the ACCT in a research setting using hypothetical vignettes. In clinical applications, the same set of 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. We have used the ACCT in this manner in long term care settings.

Components of the ACCT Interview

The ACCT begins with a values interview to understand the values, preferences, and approaches the individual uses in making medical decisions. Then, the ACCT assesses four decisional abilities: understanding, appreciation, reasoning, and expressing a choice. The ACCT has several innovations, namely: (1) Understanding is assessed with a cued procedure to minimize memory demands; (2) Appreciation is assessed with two subscales, distrust and foresight; (3) Reasoning is assessed with two subscales, rational and values based reasoning; and (4) the addition of values assessment component.

Values

Three key values domains relevant to healthcare decision making were identified based on a survey of the literature and pilot studies^{60,61}: (1) Impact of choices on valued activities and relationships; (2) Deference to others in decision making; (3) Influence of religion and views on quality of life. Each of these domains was selected based on research suggesting their importance in medical decision making. The characteristics and sources of the values items are summarized in Table 3.1.

Valued Activities and Abilities

In evaluating treatment choices, individuals may consider whether various treatment outcomes comprise states “worse than death” or otherwise affect quality of life in unacceptable ways⁶²⁻⁶⁴; such values ratings are predictive of treatment choices^{62, 65-67}. Similarly, treatment choices can be made in view of how they impact valued relationships. Patients are often very concerned about the impact of the illness and treatment on loved ones, with many older adults in particular expressing concern about being a burden to their families⁶⁸.

Preferences for decision-making participation

Consent capacity assessment assumes the engagement of a patient who is interested to participate in making his/her own medical treatment decisions. This model is consistent with the bioethical emphasis on patient self-determination in the American medical system. However, individuals differ in the extent to which they desire control over treatment decisions, based on generational, cultural, and personality factors. Evaluators should be aware that individuals with certain decision-making styles may be relatively unmotivated to participate in, or may not perceive the relevance of, a decision-making capacity assessment.

Older cohorts were socialized during a time when patients had less active involvement in medical decision making. Therefore, older adults today may take a less active role in seeking illness-related information and be more likely to assume that family members or physicians will make medical treatment decisions for them⁶⁹⁻⁷¹. Moye and Karel⁷² noted this tendency in their older research subjects, some of whom seemed reluctant to participate in medical decision-making capacity discussions. This difficulty was evident in responses from participants such as this one: “I place all the decision making in the doctor’s hands where it should always be, never tell him falsely of things; so a long time ago I placed myself in the hands of the doctor.”

Many cultural groups, including Asian- and Hispanic-Americans, believe that the individual patient should not be burdened with diagnostic or prognostic information and/or that decision-making responsibility belongs to, or is shared with, the family^{73, 74}. Some individuals who score sub-optimally on standardized measures of consent capacity may do so because they are less engaged, or less comfortable, in a process of independent medical decision making.

Individuals also differ in their interest or motivation to participate actively in medical treatment decision making, based on personality style. People vary in the extent to which they believe their own actions will have an impact on important outcomes in their life, as compared to the influence of chance or powerful others, including decisions made within the realm of health outcomes. This “health locus of control”⁷⁵ construct has genetic and environmental determinants⁷⁶, and predicts many aspects of health care decision-making and behaviors across diagnostic and cultural groups⁷⁷⁻⁸⁰. Persons with “external health locus of control” may prefer to defer decision making to their doctors or others. In addition, for a variety of personal and interpersonal reasons, many people prefer a collaborative style of decision making wherein they consider the risks and benefits of different treatments actively with the help of loved ones, doctors, clergy, or others⁸¹⁻⁸⁴.

Conceptions of quality of life

An important construct relevant to individual differences in medical treatment decision-making is quality of life⁸⁵. The extent to which individuals value preservation of life at all costs versus maintaining a certain quality of life, and what defines quality of life for different individuals, depends upon deeply held values and beliefs influenced by life experience, religious/cultural background, and personality factors.

Various strategies have been used to evaluate how an individual's conception of quality of life might influence medical treatment decisions. For example, patients might be asked to evaluate treatment options with respect to their impact on valued life activities or whether certain scenarios are considered states or fates "worse than death"⁶²⁻⁶⁴. While an individual's sense of what would be a tolerable or intolerable quality of life may change with changing life circumstances⁸⁶, the patient's responses to questions about valued life activities may illuminate why various treatment options were selected or rejected in the current capacity evaluation. The evaluation should determine whether the stated treatment choices are consistent with the individual's conceptions of quality of life.

It is critical to understand how salient life experiences, such as previous experience with life-threatening illness in oneself or others, or strongly held religious or cultural values, can influence participation in decision-making capacity assessment. For example, African-Americans are more likely to choose life-sustaining medical treatments, with less concern about "quality of life," than Caucasian Americans⁸⁷⁻⁸⁹. An individual's experiences with illness or caregiving may also influence medical treatment choices⁹⁰⁻⁹². Life experience may be an especially strong predictor of decision-making in older adults, who tend to focus more on interpersonal and experiential elements of problems than younger adults⁹³. Higher religiosity relates to treatment choices aimed at preserving life⁹⁴. Also, those who value quality of life over length of life are more likely to refuse life-sustaining treatments^{94,95}.

Table 3.1. Values Components and Sources of Items

Values Component	Subscale	Adapted from:
Impact of Choices on Valued Life Activities and	1. Concern for Impact on Daily Activities	Ditto et al. ⁶² , Pearlman et al. ⁹⁶
Valued Relationships	2. Concern for Impact on Family	Pearlman et al. ⁹⁷ , Karel ^{60, 61, 90}
Deference to Others in Decision Making Participation	3. Desired input from doctor	Blackhall et al. ⁷³ , Karel ^{60, 61, 90}
Influence of Religious or	4. Desired input from family	Blackhall et al. ⁷³ , Karel ^{60, 61, 90}
Quality of Life Beliefs	5. Religious Concerns	Cicirelli, et al ⁹⁴
	6. Quality v. length of life	Doukas & McCollough ⁹⁸ , Cohen-Mansfield et al. ⁹⁵

Decision Making Abilities

Understanding

Existing Approaches. Understanding is typically assessed by disclosing information about a diagnosis and treatments, 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 reviewed above, finds good content validity (agreement between methods) and criterion validity (association with neuropsychological tests and expected impairment in patient populations), 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 while the subject follows along with a bulleted 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 use of a list helps to focus the assessment of understanding on comprehension rather than recall.

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 treatment⁴⁴. 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 treatment³⁵ or why the physician is recommending treatment⁵⁹. More direct approaches ask the individual yes/no questions about whether the doctor is trying to incur harm versus benefit^{99, 100}. Empirical analysis of these approaches finds poor content and criterion validity, 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 both intend 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”⁴⁴. The Foresight subscale is geared to individuals who fail to acknowledge the disorder or benefits of treatment, not due to psychiatric-linked difficulties in reality testing, but due to executive-linked difficulties in presuming conditions and future states.

Reasoning

Existing Approaches. Most approaches to reasoning emphasize rational reasoning, by asking the individual to identify the risks and benefits or rational reasons^{35, 43, 44, 100} for their choice, or to compare risks and benefits⁴⁴. Some instruments ask the evaluator to rate the logical consistency⁴⁴ or adequacy of insight and judgment⁴³. Empirical analysis described in the introduction finds fair and mixed content and criterion validity for these approaches. Further, although some commentators note the importance of evaluating reasoning in light of an individual’s personal or cultural values^{1, 43}, 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 the “rationality” of decision making processes. Two items use two slightly different approaches – namely prompts to provide rational reasons with a follow up to directly compare the 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. Individual’s are asked to explain how the treatment choice does or does not affect aforementioned valued activities and relationships.

Communicating a Choice

Existing Approaches. The ability to convey a treatment choice appears relatively straightforward to assess – asking the individual to state a choice, and perhaps confirm the stability of that choice over time. The empirical evidence for this standard is somewhat difficult to evaluate because of restriction of range problems. That is, most patient samples described in the research literature receive “full credit” for measures of communicating a choice. As such, the narrow range of responses restricts the values obtained in statistical studies of content and criterion validity. We conclude that communicating a choice is an ability with good face validity, and a threshold ability – i.e., often present and 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.

Table 3.2 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 bulleted list is left out for reference.	HCAI ³⁸ , MacCAT-T ⁴⁴ , pilot study on procedure
	U2. Treatment	8-16		
Appreciation	A1. Distrust	2	Doubt about the benefit of treatment; Concerns about harm from doctor	MacCAT-T ⁴⁴ , POD ⁴⁵
	A2. Foresight	2	Planning for chosen treatment; Projection of status after treatment	CCTI ³⁵ , CSA ⁹⁹
Reasoning	R1. Rational	2	Compare and contrast treatments; List rational reasons for treatment	HCAI ³⁸ , MacCAT-T ⁴⁴ , CCTI ³⁵
	R2. Values	2	Treatment consequences for valued activities; Treatment consequences for valued relationships	New
Expressing a Choice	C1. Naming	1	Naming two choices	HCAI ³⁸ , MacCAT-T ⁴⁴ , CCTI ³⁵
	C2. Expressing	1	Statement of one consistent choice	HCAI ³⁸ , MacCAT-T ⁴⁴ , CCTI ³⁵

^aThe 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.

Vignettes

Three standardized vignettes were developed to represent a range of treatment for acute illness, chronic illness, or advanced illness, with a range of risk, complexity, and doctor recommendations as shown in Table 3.3, and provided on the next page. The first vignette presents a choice of medication or no medication for the treatment of rheumatoid arthritis. The rationale for the first vignette was to describe a condition that would involve pain and functional limitations – salient concerns for some people¹⁰¹, with a treatment that could address these symptoms but potentially cause cognitive or affective side effects – also salient concerns. An alternative form of this vignette, developed for an earlier study, is also provided.

The second vignette reviews the choice for CPR or not, akin to an advance directive and based on the work by Edelstein¹⁰². However, we found in our previous studies that most reasonably healthy individuals choose CPR in the event of cardiac arrest – so what was needed was to create a context of reduced quality of life in which some would be less likely to choose CPR. This vignette also touches on key values issues such as 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 studies⁴⁷. The rationale in developing the third

vignette is to present a somewhat 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.

Table 3.3. Description of vignettes

Vignette	# of facts	MD Recommends	Risk	Type	Adapted from:
Medication v. No Medication	12	For Medicine	Lowest	Ordinary Treatment	HCAI ³⁸
CPR v. No CPR in the context of reduced quality of life	16	None	High	Advanced Care Planning	HCAI ³⁸
Surgery v. Amputation for non-healing toe ulcer	24	None	Middle	Ordinary Treatment	Construct Validity study ⁴⁶

Vignette 1-A

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 1-B

You have a problem regulating your blood sugar. It causes problems with seeing and with circulation to your legs. It makes it 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 your risk for problems with your eyes and legs, and make it easier to take care of yourself. The risk of taking the medication is that your sugar could get too low and make you confused or drowsy. The risk of not taking the medication is that your vision may be affected or you may experience reduced or unpleasant sensation in your feet, and these problems may 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. This is called an advance directive. 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 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.

Chapter 4. Pilot Sample Characteristics and Procedures

Description of 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 more; (b) primary language English, and; (c) ability to participate in a one hour interview. Patients in the dementia group carried a clinical diagnosis of dementia; most were referred from specialty geriatric clinics. Patients in the schizophrenia group carried a clinical diagnosis of schizophrenia; most were referred from specialty psychiatric clinics. Most analyses focus on these two patient groups.

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 for 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.

Participants in the dementia group ranged in age from 65-88 years (M=77.97, SD=6.38), with a mean MMSE of 26.42 (SD=3.67). Participants in the schizophrenia group ranged in age from 60-93 (M=70.85, SD= 8.68), with a mean MMSE of 27.05 (SD=1.82). The healthy comparison group ranged in age from 61-83 (M=74.35, SD=6.38), with a mean MMSE of 28.20 (SD=1.40). Age varied significantly between the groups (F=4.58; p=.01); post hoc comparisons indicated that the mean age was significantly lower in the schizophrenic group compared to the dementia group (t=2.88, p=.006), but statistically equivalent in other group comparisons. Due to age differences, data analyses controlled for age.

In the dementia group, 2 individuals had moderate Global Deterioration¹⁰³ (GDS-4), 4 had mild (GDS-3), and 12 had very mild (GDS-2). All participants were male (recruited from VA).

Table 4.1 Patient Characteristics

Mean	Dementia	Schizophrenia	t	p
Age	77.00	71.00	2.83	.007
MMSE	26.7	27.1	0.37	.715
BSI: Paranoia*	2.65	6.40	2.83	.007
BSI: Psychosis*	2.75	3.70	0.82	.420

* maximum possible score = 20

Location of the Samples

The dementia and schizophrenia patient groups were tested at the VA Boston Healthcare System. The comparison group was tested at the VA Salt Lake City Healthcaer System.

Representativeness of Samples

Because we recruited from VA populations our sample is not representative of the U.S. population on sex and race characteristics.

Quality Control Procedures

Examiner qualifications

Capacity was assessed with the ACCT interview by trained bachelor level research assistants. Evaluators were trained to administer the ACCT interview through review of procedures, practice testing, and observation.

Quality assurance of scoring

Each protocol was scored by two research assistants; scoring discrepancies were resolved by the principal investigator (JM). To establish the reliability of scoring criteria, 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. Subscale scores were calculated by summing the item totals for each subscale. For statistical purposes an total scale score was determined by combining subscale scores for understanding, appreciation, and reasoning. Expressing a choice was not included in the total score as it is a threshold ability – that is, in order to participate meaningfully in the interviews the patients needed to be able to express some choice. A total dichotomous score (has capacity/lacks capacity) was calculated by summing the subscale scores for understanding, appreciation, and reasoning, and assigning a score of 0 to protocols whose total score was 2.0 standard deviations below the comparison group mean, and a score of 1 to the remainder.

Informed Consent Procedures

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.

Additional Testing

Cognitive and Psychiatric Screening

Cognitive status was assessed with the Modified Mini-Mental State Exam (3MS)¹⁰⁴, an extended version of the Mini Mental State Exam (MMSE). The 3MS yields a conventional MMSE score (maximum score = 30) or an extended score (maximum score = 100), and includes additional measures of executive function and delayed memory. Psychiatric status was assessed with four subscales from the Brief Symptom Inventory (BSI)¹⁰⁵: Anxiety, Depression, Paranoia, and Psychosis. Clinician Ratings

We obtained clinical ratings of capacity for a subsample of the dementia and schizophrenic patients from two sources: patients own primary care clinicians who had regular clinical contact with the patient, and expert clinicians who had no regular clinical contact with the patient.

Primary Care Clinician Ratings

Thirty-two of the 40 patients in the dementia and psychiatric 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 of these clinicians responded to our request to provide a clinical opinion on the patients 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 on the basis of audio tape recordings of the third vignette in the ACCT interview. Ratings were provided on a six point scale and also dichotomized for analyses.

Chapter 5. Reliability and Validity

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 $\alpha = .96$ based on all capacity items ($n = 56$) across three vignettes for all 40 patient protocols. Internal consistency reliability was $\alpha = .88$ (16 items) for Vignette One, $\alpha = .88$ (18 items) for Vignette Two, and $\alpha = .91$ (22 items) for Vignette Three. Internal consistency reliability was highest for understanding ($\alpha = .91$; 26 items), followed by appreciation ($\alpha = .88$; 12 items), reasoning ($\alpha = .82$; 12 items), then communicating a choice ($\alpha = .66$; 6 items).

Validity

Association of ACCT with 3MS

One measure of validity is to compare scores on the ACCT with those on standardized cognitive measures. The instruments would be expected to have a moderate positive correlation –not necessarily a high correlation as the instruments measure related but different constructs (ACCT assesses specific decisional abilities while 3MS assesses global cognitive functioning). In the patient sample ($n = 40$) the total ACCT score was moderately correlated with the total 3MS score ($r = .47$; $p < .01$) and total MMSE score ($r = .50$; $p < .01$). The total ACCT score was not significantly correlated with total BSI score ($r = .25$; NS) or any BSI subscales.

Table 4.2. Correlation of ACCT Ability Scores, Cognitive, and Psychiatric Ratings

	Understanding Disorder	Understanding Treatment	Appreciation Distrust	Appreciation Foresight	Reasoning Rational	Reasoning Values	Choice Naming	Choice Expressing
MMSE	.57*	.60*	.16	.25	.62*	.41*	.54*	.11
3MS Orientation	.35*	.49*	.12	.17	.43*	.34*	.36*	.27
3MS Recall	.46*	.47*	.00	.09	.49*	.29*	.38*	.05
3MS Executive	.60*	.67*	.14	.15	.56*	.31	.51*	.33
BSI Paranoia	-.17	-.08	-.39*	-.23	-.09	-.33*	-.22	-.13
BSI Psychosis	-.16	-.14	-.25	-.27	-.28	-.19	-.13	-.10

In summary, Understanding, Reasoning, and Naming a Choice are associated with cognitive functioning, with Understanding and Rational Reasoning having the highest correlations with overall cognitive impairment and specific cognitive domains. Executive items had the highest correlation with decisional abilities. Appreciation as Distrust and Values Reasoning are associated with paranoia symptomatology on BSI.

These findings suggest that cognitive and psychiatric symptomatology may impact different decisional abilities. In particular, paranoia may have a role in decreasing ability to Appreciate the benefits of treatments when assessed as doubts or fears of harm, and to relate treatments to valued activities and relationships. Executive dysfunction may impact the ability to rationally manipulate treatment risks and benefits, and to understand diagnostic and treatment information.

Association with Clinician Ratings

Another measure of validity is 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 possible low reliability in either the ACCT or the clinical ratings, as well as 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.

Dichotomous ratings of capacity between the ACCT and PCP ratings for 27 subjects agreed 82% of the time ($\kappa = .44$; $p < .01$). Discrepancies were noted in seven cases where the clinicians found the patients to have capacity and the ACCT did not.

Dichotomous ratings of capacity between the ACCT and a consensus ratings of three experienced clinicians for 12 subjects agreed 75% of the time ($\kappa = .50$; $p < .05$). Again, discrepancies were noted in three cases where the clinicians found the patient to have capacity and the ACCT did not – suggesting a less stringent standard deviation cut-off on the ACCT may be more consistent with clinician ratings, or that clinicians consider other factors in leading them to more lenient ratings.

Group Differences

Another indicator of validity is group differences—namely do patient groups where some degree of incapacity is expected perform lower on the instrument than cognitively healthy comparison groups. where you would expect some degree of incapacity performing lower on the measure than cognitively health groups. As shown in Table 4.3, patients with dementia or schizophrenia perform lower than the healthy comparison group on measures of understanding, appreciation as foresight, and reasoning. Patients with schizophrenia perform lower than patients with dementia or the healthy comparison group on appreciation as distrust.

Table 4.3. Group Differences on Decisional Abilities (Vignette three)

	Score Range	Dementia N=20	Schizophrenia N=20	Comparison N=29	F	Post Hoc
Understanding Disorder	0-8	4.25	4.65	6.11	5.61*	A, B
Understanding Treatments	0-16	9.95	9.80	13.16	4.02*	A, B
Appreciation Distrust	0-4	3.75	2.50	3.95	13.71*	B,C
Appreciation Foresight	0-4	2.60	2.25	3.63	6.91*	A, B
Reasoning Rational	0-4	2.75	2.50	3.89	7.44*	A, B
Reasoning Values	0-4	2.60	1.89	3.74	12.16*	A, B
Naming Choices	0-2	1.45	1.25	1.95	5.06*	B
Expressing A Choice	0-2	1.85	1.65	2.00	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

Relation of Decisional Ability Scales Across Three Vignettes

In Vignette One, the majority of both patient groups chose to take the medicine (80% schizophrenia, 95% dementia) In Vignette Two, the majority of both patient groups chose to have CPR (80% schizophrenia, 70% dementia). For Vignette Three, groups varied slightly in their choices, with individuals in the schizophrenic group less likely to choose amputation. In patients with schizophrenia, 45% chose amputation, while 65% of those in the dementia group chose amputation, and 88% of those in the control group chose amputation ($\chi^2=8.42, p<.08$).

On Vignette Three, 80% of the patients with schizophrenia and 75% of the patients with dementia were received a dichotomous summary score of “lacks capacity,” in comparison to 21% of the control comparison sample. All groups were minimally impaired on understanding (35% in the dementia and schizophrenia groups, 5% in the primary care group), whereas rates of impairment were higher for appreciation, reasoning, and communicating a choice.

There was strong positive correlation for decisional abilities as measured using different vignettes.

Table 4.4. Correlations Between Vignettes

Ability	Vignette 1&2	Vignette 1&3	Vignette 2&3	Mean Correlation
Understanding	.59	.52	.81	.64
Appreciation	.83	.69	.58	.70
Reasoning	.51	.70	.44	.55
Communicating a	.38	.53	.44	.45
Mean Correlation	.58	.61	.57	

Chapter 6. Administration

This instrument was developed based on the Hopemont Capacity Assessment Interview (Edelstein et al), the Capacity to Consent to Treatment Interview (Marson et al), the MacCarthur Competency Assessment Tool – Treatment (Grisso and Appelbaum), the California Scale of Appreciation (Saks et al), and inter-instrument comparisons by our research team. Although more than 90% of the items are new, item models, content, and format have drawn from these instruments.

When used clinically, an instrument for the assessment of decision making ability should be applied in the context of a comprehensive evaluation including consideration of diagnosis and prognosis; cognitive strengths and weaknesses; individual and cultural differences; values, hopes and preferences of the individual; situational and environmental factors. Special attention should be paid to clarifying the appropriateness of the referral and obtaining informed consent. These issues are further described in practice guidelines (Baker et al., 1998 as well as other sources (Moye, 1999; Grisso, 2003)).

As in any testing situation, the examiner should insure that the individual is as medically stable as possible, and can see and hear the interviewer and the instrument stimuli as much as is possible. Obviously, the individual should be as emotionally and physically comfortable as is possible, and should be assessed in a quiet and confidential location.

In general, the instrument should be administered with prompts to help the individual articulate what might be a rather automatic and internal decisional process. This instrument also uses bulleted lists of information to aid those individuals with hearing or memory problems. The use of bulleted lists diminishes the extent to which the interview is more purely a memory test. In the instructions, put out a new card when it says “change card”; add an additional card (keeping out the first) where it says “add card”.

Some specific tips for administering the interview, based on the instructions for the HCAI, follow:

During the introductory section of the interview, if the individual is unable to describe a risk or a benefit, as him/her to use risk or benefit in a sentence.

While assessing Understanding if the initial answer is incorrect, state the correct answer which follows each question. If the initial answer is irrelevant, repeat the question. If the individual appears to be having some trouble understanding the question, re-phrase the question to try to maximize understanding of the question.

When asking about Choices, if only one choice is mentioned, ask the interviewee “You gave me one choice. What are some others?” If person says “it” for for one of the options, prompt for what “it” means. If the person still only gives one choice, then state the other choice.

When assessing Appreciation, draw the individual out. If he or she says there are or are not reasons to doubt, ask him/her to explain why. If the individual states there is nothing to do to plan or prepare, ask if there is anything at all they might do.

While assessing Reasoning, if the interviewee is unable to answer the questions regarding his/her rationale, ask him/her to describe some possible risks and benefits or describe what might happen if different decisions were made. Prompt for both risk and benefits. If person says, “there are no risks” ask what else could happen, or if person says, “the risks are minor” as what they are, or if they say, “what the doctor, recommends” ask what that is. If the interviewee says there are no everyday or interpersonal consequences to the decision, ask him/her to explain why not.

Chapter 7. Scoring General Instructions

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. General scoring rules are as follows. For understanding, one point is given for each key fact correctly stated or paraphrased. For other items two points are given for accurate responses; 1 point for vague or ambiguous responses, and 0 points for incorrect responses. Detailed scoring criteria are provided in appendix C.

Chapter 8. Interpretative Considerations

Considerations in the Evaluation of Consent Capacity

Evaluation of consent capacity includes several steps: evaluation of the diagnosis and its symptoms; assessment of decisional abilities; exploration of values; and, weighing of these factors in the context of ethical principles of beneficence and autonomy¹⁰⁶. This evaluation should be preceded with an investigation of the referral question and an effort to obtain informed consent for the evaluation from the patient.

Referral Clarification and Informed Consent

A referral to evaluate consent capacity most often occurs in two contexts: (a) an acute or long term care medical setting where a patient with noted cognitive or psychiatric illness is refusing medical treatment (such requests for evaluations often come from attending physicians who seek clarification about the patient's capacity to consent); (b) a hospital, long term care, or community setting where a clinician, family member, service agency, or legal professional is seeking guardianship due to questions about a specific urgent medical decision or a series of current and anticipated medical decisions. In both situations, it is important to clarify the specifics of the case—what specific treatment issue is now at hand, the facts and nuances of the particular condition and treatments, and whether there are any other decisions for which capacity is questioned. At times, a referral for capacity evaluation represents a conflict between the patient and the provider or family. In these cases it is useful to clarify if a capacity evaluation will resolve the conflict by granting decisional authority to one person, or if the situation would be better addressed through an intervention that mediates the conflict. On occasion, a capacity evaluation may be requested for guardianship when there are already other proxy mechanisms in place. For this reason it is always important to clarify whether the patient has already appointed a durable power of attorney for healthcare, recorded other advance directives, or initiated other surrogate decision-making mechanisms.

Of course the evaluator will want a firm sense of history of decisional problems, and the social and contextual issues. Who is the patient's family? How much are they involved? What is the quality of the relationships? Are there other sources of social support? Finally, the evaluator will need a sense of the urgency of the request and when a decision on consent capacity will need to be rendered.

Assuming the patient is communicative, the evaluator must attempt to obtain informed consent for the evaluation of capacity. The main goal is to inform the patient of the potential risks in cooperating with a capacity evaluation. The evaluator should briefly explain why she or he has been called to evaluate capacity, what is involved (interviews, tests), the purpose of the evaluation, the potential risks (the patient may lose the right to make autonomous decisions; the patient may have a guardian appointed), and the potential benefits (information gained may help in planning for the patient's treatment). The patient's reaction to each of these elements should

be described in the evaluation report. Three outcomes are possible: the patient consents, the patient won't consent (refuses), or the patient can't consent or refuse (lacks the capacity to consent to the evaluation). In the latter situation, some patients will comply with the evaluation but show questionable comprehension of the risks and benefits. These same decisional deficits may be affecting the patient's capacity to consent to treatment. In such cases it is typical to note the patient's assent, detailing any areas of questionable ability to consent to the evaluation (in the absence of outright refusal). It is ethical to continue with a capacity evaluation for patients who are unable to fully consent to the evaluation, as long as the evaluator has attempted to obtain informed consent and has fully disclosed the risks of the evaluation. However, a referral where there is questionable capacity to consent to a capacity evaluation does not, in itself, obviate the need to disclose the risks of the evaluation and attempt to obtain consent.

Assessment of Diagnosis

Medical, psychiatric, and neurocognitive disorders potentially impacting treatment decision making should be evaluated through examination of history, and appropriate medical records including laboratory and imaging results. Where appropriate (e.g., in cases in which an individual is not profoundly impaired), capacity assessment should include structured assessment of psychiatric symptomatology through standardized rating scales and/or neurocognitive abilities (e.g., attention, memory, executive function, language) through neuropsychological assessment. In most cases, a full neuropsychological battery is not necessary, but focused testing in areas of decisional deficit may be useful in clarifying the extent of the deficit in brain functioning.

Assessment of Decisional Abilities

In assessing decisional abilities, clinicians may utilize a capacity instrument or a clinical interview. A few suggestions for assessing decisional abilities through clinical interview follow.

It can be helpful to begin with the patient's perception of the situation by asking questions such as: what is your understanding of your problem/diagnosis; what is your understanding of the prognosis, or what will happen if the problem is not treated; what are the treatment options; what do they involve; how will they affect your daily life; how will each help; what do you want to do. If diagnostic and treatment information has not already been disclosed to the patient, it is more useful to first disclose the information to the patient and assess understanding and appreciation. Even in cases where the information has been disclosed, it is typically important to review this information with the patient, as some questions of capacity arise from patients' refusing treatment in the context of inadequate treatment description. Unfortunately, some obvious oversights can occur, such as the patient being given information in English although their primary language is not English.

For more in depth assessment of understanding, the method suggested by Grisso and Appelbaum (1998) may prove useful. Disclosure is followed by questions that encourage patients to state "in their own words" their understanding of the information just provided. This approach can be augmented by providing the information in writing using a simplified, bulleted list, diminishing the memory component for the assessment of understanding, focusing instead on comprehension.

For some patients, it is useful and, in other cases, necessary to assess understanding through yes/no questions. For example, consider a patient with advanced MS who refuses hospital transfer, although this was at odds with a previously provided advance directive. In assessing his understanding of his condition, a series of yes/no questions was used, such as: does MS affect the brain; is it a disease whose effects get worse over time. In this case, the patient answered “no” although information about the condition had been disclosed to him just before the questioning. His responses to these and other yes/no questions indicated he was unable to understand information about his condition.

In assessing appreciation, it is suggested that evaluators explore two means by which appreciation deficits may become manifest: either through disavowal of the condition and treatment benefits, or through difficulty in foresight (projecting treatment outcomes into the future). In our clinical experience, the former may be more impacted by psychiatric illness, whereas the latter may be impacted by neurodegenerative disorders, affecting the frontal lobe (such as frontotemporal dementia). In assessing disavowal, a screening strategy can be useful. First ask a neutral question such as: “What do you believe is really wrong with you now” or “Why is the doctor recommending the treatment”. If answers suggest doubt or concern on the part of the patient, more directed questions may follow such as: “do you have doubt that the treatment will help you” or “do you believe the doctor may try to harm you.” Another way that appreciation has been assessed is to ask “what do you believe will happen to you without treatment.” Some patients with dementia will not express disavowal based on paranoid processes, but will have trouble projecting treatment benefits due to problems with foresight. In this case, it can be useful to ask “what do you think will happen to you with the treatment” or “what do you think your life will be like after the treatment.” In our experience, some patients with dementia are acquiescent to a doctor’s recommendations, and profess they will be “fine,” but when detailed follow up questions are asked, they are unable to appreciate how the condition may affect them over time, or how the treatment may or may not ameliorate the problem.

In assessing reasoning, several approaches may be used. Grisso and Appelbaum (1998) recommend questions that direct the patient to explicitly compare treatment alternatives, such as “why do you think treatment x is better than treatment y” or “what is it about treatment x that makes it seem better for you.” Another approach is to attempt to elicit the reasons for a treatment decision by asking a question such as “tell me all the reasons you decided to do treatment x” or “what risks and benefits did you consider in choosing treatment x.” At this point in the interview, the expert may wish to consider the consistency of choices with values. For example, the evaluator could ask the patient to explain how various risks and benefits impact valued life activities, such as “how would the tremors that may be caused by this medication affect your ability to do things that you enjoy.” It is often useful to assess the patient’s valued activities, relationships, and cultural/religious beliefs prior to the assessment of decisional abilities, as this creates a reference for in depth questioning about the relationship of choices to stated values, preferences, and attitudes during the assessment of reasoning.

The assessment of the ability to communicate a choice is straightforward, by asking the patient to state which treatment is preferred. This may be done at both the beginning and end of the interview to evaluate the consistency of a choice.

Preferences for decision-making participation

It is important to assess the patient's motivation and comfort with making his/her own medical treatment decisions. For example, the evaluator can ask: how do you usually make decisions about your medical care - alone or with the help of family or others; is there anyone you would want to help you make this decision; would you prefer that someone else make this decision for you; who would you trust, and why; is there anyone you would not trust to make decisions for you. After exploring the patient's level of interest to participate in medical decision-making, and especially if s/he expresses discomfort to participate, it is important to ask: is it alright to continue to guide you through your thoughts about this medical decision; (if not) is there someone you would prefer I talk to?

Also, the evaluator can assess the patient's attitudes about proxy decision-making. For example: if at some point you were so sick that you could not speak for yourself, who would you want to make decisions on your behalf; how do you want that person to make decisions, based on what they think you would have wanted ("substituted judgment" standard), or on whatever they feel is best at the time, all things being considered ("best interest" standard)?

Conceptions of quality of life

The assessment of values should focus on what makes life worthwhile for this particular patient and, on the other hand, would there be any life situations this patient would find intolerable. In addition, it is important to assess the individual's perspective on preserving life in any condition versus concern for maintaining a minimally acceptable quality of life. Here, asking about specific religious, cultural, or moral beliefs that may influence treatment decisions is important, especially regarding life-and-death medical decisions (e.g., whether to start or withdraw a life-sustaining treatment).

Regarding quality of life, it can help to ask about previous experiences with illness and medical care, for the patient or others he/she knows. Experiences with pain, medical complications, loss, or related suffering—as well as positive experiences with healing, caregiving, or coping with disability—can profoundly influence current medical care decisions. It can be helpful to ask explicit questions, such as, can you imagine any circumstances in which you would rather be dead than remain alive ("fates worse than death"). It may be useful to assess what specific daily activities or abilities are most central to this patient's conception of a life worth living. For example, it can help to ask the patient how important it is to be able to communicate with loved ones, to think clearly, to move around (e.g., out of bed), to chew and swallow food, to take care of one's personal hygiene, to enjoy activities such as reading, television, and music. It can also help to ask patients what their worst fears are when they think about difficult medical decisions.

Interpersonal/social context

Medical treatment decisions do not occur in a social vacuum. It can be important to assess the extent to which patients may be making decisions in consideration of the interests of others, or as influenced by the feelings of others. Patients may consider others' interests in valid ways

consistent with their own values (e.g., concern for being an emotional or financial burden to one's spouse), or in ways subject to undue influence by others (e.g., over-acquiescence to the values of others for fear of losing the relationship). Also, the current social context may greatly influence treatment decisions. For example, an elderly patient may want to risk a difficult surgery if the spouse was still alive, but be ready to accept death if widowed; or, a patient may want to survive for a specific event, such as the birth of a grandchild. It can be informative to ask: what thoughts do you have about how your illness or care might affect others in your life; have other people's emotional or financial interests influenced your wishes about medical care.

Formulating Conclusions

The next step is to determine the conclusions of the assessment, both general findings and capacity-related findings, and share them with the patient, medical team, and relevant family members. In many settings, the results of a capacity assessment can provide a clinical diagnosis and treatment recommendations, but should also clearly and directly answer the question of capacity, outline appropriate legal interventions and, whenever possible, address less restrictive alternatives. Here, the clinician must balance the information at hand about the diagnosis, cognitive and psychiatric symptoms, and decisional functioning in view of interactive and contextual factors, such as the person's values, goals, preferences, history and the situational risks. No cookbook exists for combining these factors; capacity conclusions are a professional clinical judgment. However, when the evaluator has carefully collected information regarding all the components, including standardized testing of cognition and behavior, the key elements to make such a judgment are at hand.

We find that capacity conclusions fall into one of three categories: (a) Persons with gross and severe impairment; (b) persons with moderate impairments in some areas of function; and, (c) persons with subtle or variable impairments, unique perspectives or values, or eccentric decisional styles. Detailed evaluation of a person with obvious and severe impairment such as those who are unconscious following an accident or medical trauma, those in a persistent vegetative state, or those with advanced cases of dementia is not appropriate. In situations in which the degree of impairment is extensive, the treating physician's documentation of the case is often sufficient to establish incapacity, and frequently leads to the appointment of a surrogate decision-maker with plenary powers. Assessment of individuals with moderate impairments, or who have significant impairments in some areas but not others, although not cursory, can be relatively straightforward. Following assessment of the diagnosis, functional abilities, and contextual factors, the assessment results should naturally lead to conclusions about the individual's ability to make decisions in various domains, and should reveal more information about strengths and weaknesses than could be determined from a clinical diagnosis alone. Patients with subtle or variable impairments, unique values, or eccentric styles are indeed more challenging to assess. In these cases, more in depth evaluation using capacity instruments and values interviews can help the clinician to sort through the issues of autonomy versus protection.

Dispositional element

In some cases, the expert's job is to describe his or her capacity findings and then to leave the determination of legal capacity and appropriate actions to a judge. In other cases, the evaluator will offer recommendations for disposition. For example, the expert may conclude that a substitute decision-maker is needed and recommend that a previously appointed healthcare proxy be activated, or, if unavailable, that the hospital implement its policy of obtaining consent from the next of kin. Other times, the evaluator will recommend that a medical decision await treatment of an underlying psychiatric or neurocognitive condition, when time allows, prior to pursuing medical treatment. The evaluation may also uncover decisional aids or cultural, language, or religious concerns that should be addressed as consent is obtained.

Case Example

This is a summary of an evaluation for consent capacity. In the actual case, the full report provided more details on his social, medical, and psychiatric history and specific test results. This case illustrates several points: the importance of assessing an individual in their preferred language; the importance of assessing over several occasions when the patient may be delirious; the difference in abilities for simple versus complex decision making; the issue of consistency of stated values/beliefs with treatment choices, and; capacity evaluation as an opportunity to make treatment recommendations.

Referral Question This is a 65 year old, white Hispanic, Spanish (preferred) and English speaking male, residing in a nursing home. He was referred by his primary care physician who requested an evaluation to assess patient's ability to consent to dialysis (patient is expressing reluctance/refusal). He has previously appointed his cousin, Maria, as his Health Care Proxy.

Informed Consent The patient was informed of the purpose of the evaluation (i.e., assessing his capacity to consent to dialysis), its risks and benefits, and his right not to cooperate. Mr. R. demonstrated limited but adequate understanding of the information. He understood the purpose was "to help the doctor help me," that he did not have to participate, and that the results would be provided in a report to his doctor.

Current Diagnoses Medical diagnoses include Hepatitis B and C with associated cirrhosis and fluctuating mental status (hepatic encephalopathy), diabetes mellitus, chronic renal failure with progressively increasing creatinine, polysubstance dependence in remission, and schizoaffective disorder-depressed type. He has had multiple psychiatric hospitalizations with hallucinations and suicidal ideation. His medications are: Insulin, Quetiapine 100 mg bid, 400 mg qhs, Oxycodone 5-10 mg prn for pain, Omeprazole, 20 mg po qd, Salmeterol inhl, oral 1 puff bid, Spironolactone BID Hold for BP 100 systolic or less; also, he takes eyedrops, multivitamin, acetaminophen prn for pain, stool softener prn.

Social History Mr. R grew up in Puerto Rico. His father is deceased, his mother, who has schizophrenia, is alive. Most of his family is in Puerto Rico. He has limited contact with his family except his cousin, Maria, who lives locally. He has a long history of unemployment and homelessness secondary to substance abuse and mental illness. He has never been married.

Behavioral Observations Across the different days of testing, Mr. R consistently exhibited depressed mood, flat affect, difficulty sustaining attention, poor eye contact, and auditory hallucinations. These symptoms appeared to be frequent, severe, and chronic in nature and reflected Mr. R's current baseline functioning. He was otherwise alert and oriented x 3. Mr. R. denied having suicidal or homicidal thoughts. He was able to engage in simple meaningful conversations. He had good insight into his mental illness and mixed insight into his medical diagnoses.

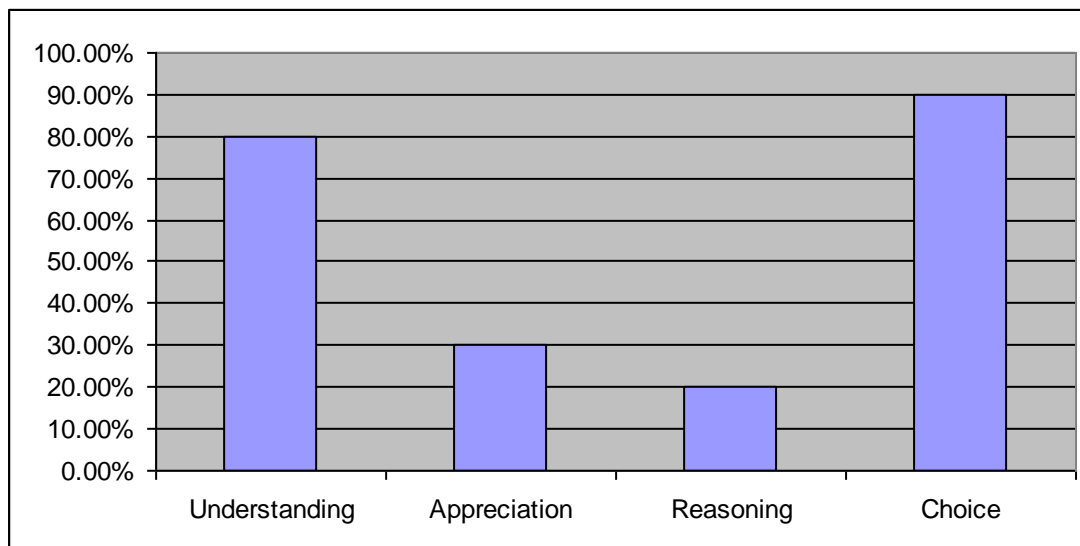
Procedures All interviews and testing were conducted in Spanish by a Spanish-Speaking clinician. The evaluation was completed across four separate days (1 hour, 45 minutes total) to

minimize the demands on his attention and to provide an opportunity to observe him on different days and different times of day.

Cognitive Abilities On structured cognitive tests (MMSE, WAIS-III and WMS-III subtests, & Clock drawing) he had moderate impairments in attention, concentration, and immediate memory, and severe impairments in delayed memory, and judgment/planning (executive functions) (MMSE = 18/30).

Decisional Abilities On a structured interview of medical decision making adapted to the patient's condition, he had adequate understanding of his current problem, "The doctor says that my kidneys are not working because of my diabetes and I need to have dialysis, you know, when they put you on a machine to clean your blood." When asked to describe his feelings about the potential benefits of treatment (appreciation), he was reluctant, saying "I am not sure that this will work for me; I don't think that a machine can clean my blood better than my body." When asked to explain why not having dialysis is better than having dialysis (reasoning), he stated "I only want to have what is mine, and I don't want my blood outside my body going through a machine." When asked to describe what would happen without dialysis, he stated, "I hope that my body will heal by itself." When reminded that his doctor told him that he would die without dialysis, he said, "I want to live and I trust God will help my body heal without dialysis."

% Correct Decisional Abilities as Assessed on ACCT



Values Mr. R. said that what makes life worth living is: "My mother, I do not want her to suffer and I know that she will if something happens to me." When asked whether the well-being of others influences his medical decision making he said: "My mother told me to make sure I get better and that I listen to the doctors' recommendations." When asked who he wants involved in making medical decision on his behalf, he said, "My cousin Maria; I can trust her to make decisions for me if I cannot do it myself." When asked for his preferences regarding resuscitation, he said, "I want to be revived; I want to live." He was unable to fully explain his reasoning other than he just wanted to live. When asked if he had any religious beliefs that would

prevent him from having dialysis, he said, “I don’t, I just know that my body can heal with the help of God.”

Summary Mr. R’s has ongoing hallucinations and displays considerable deficits in attention, memory, and planning. He has limited judgment in caring for his medical needs. In terms of medical decision making, he displays some understanding of his medical conditions, but his appreciation and reasoning about treatments is limited. These decisional abilities are influenced by his confusion, poor memory, concrete thinking, and psychiatric symptoms associated with schizoaffective disorder and chronic delirium.

Mr. R can make simple medical decisions such as designating a family member as his Health Care Proxy. However, complex medical decisions (i.e., receiving dialysis) will tax his ability to deliberate about the risks and benefits of treatments. Mr. R’s expressed values were also not consistent with his unwillingness to consider dialysis as a life-saving medical treatment. He reported, for example, how important it was for him to follow his mother’s advice (i.e., “listen to the doctors”) and he also expressed a clear preference to be resuscitated because he wants to live. However, Mr. R was unable to fully appreciate the consequences of not receiving dialysis and was fixated on the idea that his body will heal by itself with the help of God.

Mitigating factors His performance during the interview and testing was influenced by his medical conditions, pain, and fatigue, and also may be influenced by his medications, some of which could contribute to his confusion. His mental status could improve with dialysis, which could potentially improve his medical decision making.

Recommended Actions and Interventions

- (1) If Mr. R. is alert and provided simple information in a structured manner, in Spanish, he can make very simple medical decisions. If possible, discuss situations with Mr. R. prior to receiving sedating medications and when he is not in severe pain.
- (2) For complex medical decisions, his Health Care Proxy proxy should make decisions. Mr. R. should be included in discussions.
- (3) Regarding dialysis, his Health Care Proxy should make the decision. However, it is not practical to force a patient to accept dialysis if he refuses. Thus, a discussion between Mr. R., his cousin, and the doctor should be encouraged that emphasizes why dialysis is being recommended and discuss means to make Mr. R. most comfortable during dialysis should his Health Care consent and should Mr. R assent the procedure. Given Mr. R.’s religious values, it may be useful to include a chaplain in this discussion. Finally, it may be helpful to encourage Mr. R. to try dialysis for a brief period of time to determine if he can tolerate it. The decision to dialyze could be reconsidered after there is more information as to how Mr. R. finds it.
- (4) Given Mr. R’s complex medical problems and prognosis, it is important to facilitate a discussion with family members about their understanding of Mr. R’s specific preferences and values regarding advanced illness interventions.
- (5) Ongoing assessment and treatment of his psychiatric symptoms is recommended. Given Mr. R’s ongoing hallucinations, his psychiatric treatment regimen should be reviewed.

Appendix A: ACCT Interview

Assessment of Capacity to Consent to Treatment (ACCT) Interview
©Jennifer Moye, et al.

Part 1 : Values Assessment

“In this part of the interview, I am going to ask you your opinion about your health and life. You should give your honest opinion.

Valued Activities

CHANGE RESPONSE CARD [Quality of Life]

“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). [If chosen, ask, “what is it”].

[Read through the list. Help the person to choose three things. Record the three things on the next page.

Set page aside for future reference.]

Valued Relationships

Please tell me:

Do you live:

In your own home or apartment

In a supervised living setting

For how long?

Do you live:

Alone

With loved ones

With others (ask who).

Who are the people who are most important in your life?

How close are you to them?

Not at all

Somewhat close

Very Close

Preferences for Decision Making Participation

CHANGE RESPONSE CARD [Deference Doctor]

“The next questions are about who you like to be involved when you face an important medical decision.” [Pointing to the card:] “These are the choices for the next question:”

[Read through the response categories after asking the question]

	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 my doctor to make the decision entirely for me
When you make an important healthcare decision, how much input do you want from the doctor?	0	1	2	3	4

CHANGE RESPONSE CARD [Deference Family]

[Pointing to the card:] “These are the choices for the next question:”

[Read through and point to the response categories after asking the question]

	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 my family to make the decision entirely for me
When you make an important healthcare decision, how much input do you want from family?	0	1	2	3	4

Importance of Religion

CHANGE RESPONSE CARD [Influence Religion/Faith]

The next question is about whether your faith, religious, or spiritual beliefs influence your medical decisions. [Pointing to the card:] “These are the choices for the next question:”

[Read through and point to the response categories after asking the question]

	Not at all	A little	somewhat	mostly	completely
When you make an important healthcare decision, how much do your religious or spiritual beliefs influence your decision?	0	1	2	3	4

Quality of Life

CHANGE RESPONSE CARD [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. I will ask you to tell me one of these answers [show response card and point to response categories]. You might tell me the statement is: Very False, Mostly False, that you Do Not Know, Mostly True, or Very True.”

How true is each statement for you?	Very False	Mostly False	Do Not Know	Mostly True	Very True
The quality of my life is more important than how long I live.	0	1	2	3	4
If I were very sick, I would like to do everything possible to prolong my life.	0	1	2	3	4

Part 2. Decision Making Abilities

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 1: 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?”

U2. Understanding 2: Treatment B

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

C1. Naming Choices

C1. What are your choices for treatment (in the story)?

If only one choice is given, prompt for other, e.g., “what is the other choice”.

C2. Expressing 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 plan 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: Test Stimuli

To take care of myself (e.g., bathing, dressing)
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 activities or hobbies that I enjoy

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 my doctor to make the decision entirely for me
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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 my family to make the decision entirely for me
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Not at all	A little	Somewhat	Mostly	Completely
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Very False	Mostly False	Do Not Know	Mostly True	Very True
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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.

The problem	Rheumatoid Arthritis A lot of pain Hard to care for self
Choice 1:	Get prescription medication Take it twice a day
Benefits	Decrease Pain Able to care for self
Risks	Confused or Drowsy Depressed
Choice 2:	Do not take medication
Benefits	Avoid risks of medication
Risks	A lot of pain Hard to care for self

<p>The problem</p>	<p>Stroke</p> <p>Problems think, move</p> <p>Need help, live in Nursing Home</p> <p>Can enjoy family, friends, tv, music</p>
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Choice 1:	Have CPR, if heart stops beating Dr/Nurse push chest Blow into mouth
Benefit	May Save Life
Risk	Brain damage Broken ribs

Choice 2:	Not have CPR, if heart stops beating
Benefit	Avoid Risks of CPR
Risk	Probably die

The problem	Non healing toe ulcer Infected open sore Does not respond to medication Lack of blood supply From legs to feet Infection may spread Could lead to death
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Choice 1: Surgery on artery	Incision down leg Insert new artery
Benefit	Increase blood supply Save toe
Risk	Could die Need help during 6 weeks of recovery

Choice 2: Amputation of toe	Surgeon cuts off toe Quick
Benefit	Rid of infected tissue No major surgery
Risk	Use a cane Difficulty with balance

Appendix C: Scoring Manual

Vignette #1: Medication v. No Medication for Pain for Rheumatoid Arthritis**Understanding, General Rules**

- 2** Recalls/restates content fairly clearly. Answer an exact repetition, a correct synonym or definition
- 1** Recalls/restates content but describes in a way that renders understanding uncertain. Or answer contains some content but lacks other content.
- 0** Answer is vague, obviously incorrect, or doesn't meet criteria for 1 or 2 points

U1. UNDERSTANDING: DISORDER

Q. Who has the medical problem?

A. Me or I do

1	<p><i>Answer is an exact repetition, a correct synonym or definition.</i></p> <ul style="list-style-type: none"> ▪ "Me." ▪ "I do."
0	<p><i>Answer vague or obviously incorrect.</i></p> <ul style="list-style-type: none"> ▪ "I don't have arthritis, but I do have back pain." ▪ "The doctors."

Q. What is the medical problem?

A. Rheumatoid arthritis

1	<p><i>Answer is an exact repetition, a correct synonym or definition.</i></p> <ul style="list-style-type: none"> ▪ "Rheumatoid arthritis." ▪ "Arthritis."
0	<p><i>Answer vague or obviously incorrect or doesn't meet criteria for 1 point.</i></p> <ul style="list-style-type: none"> ▪ "Pain in the joints." ▪ "Aches and pains."

Q. How is the arthritis affecting you?

A. A lot of pain in hands and joints; it is hard to take care of myself.

2	<p><i>Answer demonstrates an ability to state at least two characteristics of the condition as an exact repetition, a correct synonym or definition.</i></p> <ul style="list-style-type: none"> ▪ 1 pt = "Pain in joints or hands." ▪ 1 pt = "Hard to take care of self." "Trouble walking, washing hands."
1	<i>States only one of exact answers above.</i>
0	<i>Answer is obviously incorrect or none of exact answers above.</i>

U2. UNDERSTANDING: TREATMENT

Q. What does the doctor want you to do for the arthritis?

A. Get prescription for medication; take it twice a day.

2	<p><i>Answer demonstrates an ability to state at least two things the doctor requested.</i></p> <ul style="list-style-type: none"> ▪ 1 pt = "Get a prescription." ▪ 1 pt = "Take medicine twice a day." "Get a pill box to remember to take medicine."
1	<p><i>States only one of exact answers above.</i></p>
0	<p><i>Answer is obviously incorrect or none of exact answers above.</i></p> <ul style="list-style-type: none"> ▪ "The doctor wants him to have a shot."

Q. What are the benefits of taking medication?

A. Decrease pain; able to take care of self

2	<p><i>Answer conveys the understanding of the concept of benefit AND demonstrates an ability to state the benefits associated with the medical decision-making situation portrayed in the scenario.</i></p> <ul style="list-style-type: none"> ▪ 1 pt = "I'll have less pain." ▪ 1 pt = "I'll be able to take care of myself."
1	<p><i>Answer conveys the understanding of the concept of benefit BUT does not provide example(s) specifically relevant to the scenario or is vague (or only one of exact answers above).</i></p> <ul style="list-style-type: none"> ▪ "It's a good thing to do. It helps you." ▪ "Help stiff joints." (Note: needs to mention decreased or reduced pain for full credit).
0	<p><i>Answer is obviously incorrect or doesn't meet criteria for 1 or 2 pts.</i></p> <ul style="list-style-type: none"> ▪ "You have a choice to take it or not." ▪ "It could help you but it could also hurt you."

Q. What are the risks for taking medication?

A. Confused or drowsy; depressed.

2	<p><i>Answer conveys the understanding of the concept of risk AND demonstrates an ability to state the risks associated with the medical decision-making situation portrayed in the scenario.</i></p> <ul style="list-style-type: none"> ▪ 1 pt = "Might make you confused or drowsy." "Hazy like." ▪ 1 pt = "You might get depressed." "You'll feel down in the dumps."
1	<p><i>Answer conveys the understanding of the concept of risk BUT does not provide example(s) specifically relevant to the scenario or is vague (or only one of exact answers above).</i></p> <ul style="list-style-type: none"> ▪ "It may make it worse over time." ▪ "Side effects." ▪ "Discomfort." ▪ "May become sick."
0	<p><i>Answer does not convey understanding of concept of risk and does not provide examples relevant to the scenario, is obviously incorrect or does not meet criteria for 1 or 2 points (or none of exact answers above).</i></p> <ul style="list-style-type: none"> ▪ "It will get worse." ▪ "If you don't take it, it won't help you."

Q. What are the risks of not taking the medication?

A. Be very painful; keep from taking care of yourself.

2	<p><i>Answer conveys the understanding of the concept of risk AND demonstrates an ability to state the risks associated with the medical decision-making situation portrayed in the scenario.</i></p> <ul style="list-style-type: none"> ▪ 1 pt = "The pain will continue." "Ride the pain out." ▪ 1 pt = "I will not be able to take care of myself."
1	<p><i>Answer conveys the understanding of the concept of risk BUT does not provide example(s) specifically relevant to the scenario or is vague (or only one of exact answers above).</i></p> <ul style="list-style-type: none"> ▪ "The arthritis won't be helped and I won't feel better." ▪ "The risk is that I will have to keep seeing the doctor for my arthritis."
0	<p><i>Answer does convey understanding of concept of risk and does not provide examples relevant to the scenario or is obviously incorrect.</i></p> <ul style="list-style-type: none"> ▪ "Lead to more serious things." ▪ "I will still have problems."

Appreciation as Distrust, General Rules

- 2 Acknowledges he/she has the disorder or potential benefit of treatment, or, disagrees but offers a reasonable explanation (based on experience, different medical opinion)**
- 1 Acknowledges possibility of disorder/treatment benefits but with doubt, or disagrees but offers reasons that are vague, ambivalent, or insufficiently justified**
- 0 Does not agree with explanation of disorder/treatment benefits, with reasoning that distorts reality, or relates symptoms to implausible circumstances**

A1. APPRECIATION DISTRUST**Q. Do you have any doubts that such a medicine might help you?**

2	<i>No, or Yes with reasonable explanation</i> <ul style="list-style-type: none"> • “No, the doctor is prescribing it and I trust the doctor.” • “No, that’s part of the idea with the story – take medication to help yourself.” • “No, it’s a medication. It is for pain. The doctor gives it to you with the assumption that it will work.”
1	<i>No but questioning, or Yes with reasons that are vague, ambivalent, or insufficiently justified.</i> <ul style="list-style-type: none"> ▪ “Maybe. I do have doubts, but a benefit would be that my joints might not be sore.” ▪ “Maybe. I will know after I take the first one.”
0	<i>Yes with reasons that distort reality or relate symptoms to implausible circumstances.</i> <ul style="list-style-type: none"> ▪ “Yes. There is no magic pill. They’ve got 20,000 pills and not one of them works. Half of Africa is dying.”

Q. Would you be concerned that the doctor might be trying to harm you?

2	<i>No, or Yes with reasonable explanation</i> <ul style="list-style-type: none"> ▪ “No, I don’t.” (<i>no explanation</i>) ▪ “No, I trust the doctor implicitly.” ▪ “No. Why would he?”
1	<i>No but questioning, or Yes with reasons that are vague, ambivalent, or insufficiently justified.</i> <ul style="list-style-type: none"> ▪ “No, I just think that the doctor aims to put you away.” ▪ “Maybe. That’s a possibility. I would have more faith that the doctor would help me.”
0	<i>Yes with reasons that distort reality or relate symptoms to implausible circumstances.</i> <ul style="list-style-type: none"> ▪ “Yes, the doctor might not be trained right.”

C. EXPRESSING A CHOICE**Q. Remember that having a choice means being given the chance to do one of two or more things. What are your choices in this story?**

A. May or may not take the medicine

2	Answer demonstrates an ability to state both choices as an exact repetition, a correct synonym or definition. 1 pt = “to take the medication” 1 pt = “to not take the medication” “... or not”
1	<i>Answer reflects only one option.</i> <ul style="list-style-type: none"> ▪ “To take the medication.”
0	<i>Answer is vague, obviously incorrect, or doesn’t meet criteria for 1 or 2 pts (or none of exact answers above).</i> <ul style="list-style-type: none"> ▪ “To have to take it.” ▪ “Do it or not.”

Q. What would you do about taking the medication?

A. [States choice]

2	<i>States clear choice.</i> <ul style="list-style-type: none"> ▪ “Take the medication” ▪ “Not take the medicine.”
1	<i>Choice vague; or ambivalent</i> <ul style="list-style-type: none"> ▪ “Follow the doctor’s orders” ▪ “Do one thing for awhile to see how it goes and then do the other.”

0	<p><i>Unable to state choice, or obviously incorrect (not specific to scenario)</i></p> <ul style="list-style-type: none"> ▪ “I am not sure what to do in this case.” ▪ “You do what you think is best.”
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R1. REASONING RATIONAL

Rational Reasons/Risks and Benefits

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

2	<p><i>Answer demonstrates ability to state at least two risks and/or benefits of the treatment as an exact repetition, a correct synonym or definition.</i></p> <ul style="list-style-type: none"> ▪ “Even though it improves my condition, I could get depressed.” ▪ “I might get confused or drowsy which outweighs having less pain.” ▪ “Without medicine, I will continue having pain. With the medicine, I may be tired but I can cope with that.” ▪ “A benefit is less pain, and a risk is getting drowsy.” ▪ “Benefits are that you have less pain and you can be more active and independent.”
1	<p><i>Answer vague (or states only one either risk or benefit of the treatment).</i></p> <ul style="list-style-type: none"> ▪ “The risk is that it could get worse if I didn’t take it.” ▪ “I consider mostly the benefits of getting better and living a better life.” ▪ “I’m really concerned about the potential loss of cognitive ability.” ▪ “To ease my pain of RA. If I refused it, I would be responsible for my own possible death.”
0	<p><i>Answer is obviously incorrect or doesn’t meet criteria for 1 or 2 pts (or none of exact answers above).</i></p> <ul style="list-style-type: none"> ▪ “I had enough of things, 16 pills a day, not knowing about them... violence on TV.” ▪ “What the doctor told me about how I would feel.”

Comparative Reasons

Q. Tell me why ____ seems better than ____.

2	<p><i>Offers at least one statement in the form of a comparison of at least two options (stated or clearly implied), with the comparison including a statement of at least one specific difference</i></p> <ul style="list-style-type: none"> ▪ “Mainly because it’s going to remove pain.” ▪ “RA is a steady thing. It doesn’t go away on its own.” ▪ “RA is worse in bad weather. Once you stop taking the medicine, you might get pain again.” ▪ “If I did not take it, I would still have the pain. Having less pain will allow me to take better care of myself.”
1	<p><i>Makes a comparison statement but does not include a statement of a specific consequence, i.e., says one is better than other without saying why</i></p> <ul style="list-style-type: none"> ▪ “Anything is better than having another pill to take.” ▪ “It’s better because my doctor told me so.”
0	<p><i>Makes no comparative statements, is obviously incorrect, OR makes comparison but reason is inconsistent with facts as presented in the vignette.</i></p> <ul style="list-style-type: none"> ▪ “I have been with quite a lot of doctors. I don’t believe in taking chances.” ▪ “I don’t believe in all that science and pills and curing. I think it is witchcraft. I believe God will cure me.”

R2. REASONING VALUES**Impact on Valued Activities and Abilities**

Q. **Looking at the list we made earlier, what are the ways in which [choice] could impact _____?**

2	<p><i>Gives at least one specific consequence, or gives none with adequate justification</i></p> <ul style="list-style-type: none"> ▪ “I believe that medicine could help me take care of myself and make me feel better.” ▪ “It would relieve pain and allow me to use my hands.” ▪ “Without RA, I shouldn’t be depressed, and if I was less depressed, I could take care of my wife.” ▪ “I definitely think it will impact me. I could return to my walking and lift my grandchildren.”
1	<p><i>Answer vague or just reads from list</i></p> <ul style="list-style-type: none"> ▪ “It would be better if I didn’t take it. It will interfere with activities.” ▪ <i>Reading from list:</i> “not to have to depend on others, to have relationships with family and friends, and to move around by myself.”
0	<p><i>Gives no reasonable consequence (without justification), or states no impact when impact on choices is clear.</i></p> <ul style="list-style-type: none"> ▪ “I don’t know. That is the \$64,000 question.” ▪ “I don’t see how it would impact them.”

Impact on Valued Relationships

Q. **How would your decision affect the people who care for you?**

2	<p><i>Gives at least one specific consequence, or gives none with adequate justification</i></p> <ul style="list-style-type: none"> ▪ “It will not affect them at all if I take the medication, but if I don’t take the medicine it may affect them because I will be in pain and grouchy and mean.” ▪ “People around me want me to take medicine because I would feel better.” ▪ “It would be less care for them if I felt better, and they wouldn’t want to see me in pain. It would make a better household.” ▪ “I think it will relieve them of a lot of worrying about me. I would like to take care of myself as long as possible.”
1	<p><i>Answer vague</i></p> <ul style="list-style-type: none"> ▪ “They have to know you are taking the medication, but it’s up to you.” ▪ “May make it a little easier on them.”
0	<p><i>Gives no reasonable consequence (without justification)</i></p> <ul style="list-style-type: none"> ▪ “My sister would get my life insurance since I have no children to leave behind.” ▪ “It doesn’t matter. They don’t send me Christmas cards anyway.” ▪ “It will make me feel good.”

A2. APPRECIATION FORESIGHT

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

2	<p><i>Gives at least two things to do</i></p> <ul style="list-style-type: none"> ▪ If taking, plan for getting/using medication: <ul style="list-style-type: none"> ○ “Get the prescription and ask my pharmacist about it mixing with my other meds.” ○ “Set it in my pill box and take it twice a day.” ○ “Tell a friend to pick it up for me, and have her help fill my pill bottle.” ▪ If not taking, plan for consequences of pain getting worse: <ul style="list-style-type: none"> ○ “Do more yoga and use imagery to help me cope with pain.” ○ “Talking to my grandchildren helps me when I’m in pain, so I’ll have to see them more often.”
1	<p><i>Answer vague (or only one of exact answer above).</i></p> <ul style="list-style-type: none"> ▪ “Nothing other than what is prescribed by the doctor.” ▪ “No, I take it according to drug instructions.” ▪ “Put my medications someplace near my bed so I remember to take them.”
0	<p><i>States nothing to do or unrelated things to do</i></p> <ul style="list-style-type: none"> ▪ “May need more rest. Watch your diet. Use the same muscles for everything.” ▪ “My doctor handles that.”

Q. Do you believe you might get better without the medicine?

2	<p><i>No, or Yes with reasonable explanation</i></p> <ul style="list-style-type: none"> ▪ “No, because it is a pretty disabling condition.” ▪ “If the diagnosis is correct and I am in pain, I want to try something.” ▪ “No. As far as I heard, rheumatoid arthritis will not get better and is difficult to treat.”
1	<p><i>No but questioning, or Yes with reasons that are vague, ambivalent, or insufficiently justified.</i></p> <ul style="list-style-type: none"> ▪ “Yes, it is possible.” ▪ “No, but you never can tell what these drug companies are up to.”
0	<p><i>Yes with reasons that distort reality or relate symptoms to implausible circumstances.</i></p> <ul style="list-style-type: none"> ▪ “Yes. It already is getting better. I am not taking it!” ▪ “Yes, I’ve stopped taking medication in the past and felt better.” ▪ “No. I was taking medicine like this and now I’m in here.”

Vignette #2: High Risk/Middle Complexity/Advanced Illness Treatment**Understanding, General Rules**

- 2** Recalls/restates content fairly clearly. Answer an exact repetition, a correct synonym or definition
- 1** Recalls/restates content but describes in a way that renders understanding uncertain. Or answer contains some content but lacks other content.
- 0** Answer is obviously incorrect or doesn't meet criteria for 1 or 2 points

U1. UNDERSTANDING: DISORDER

Q. Who has the medical problem?

A. Me or I do

1	<p><i>Answer is an exact repetition, a correct synonym or definition.</i></p> <ul style="list-style-type: none"> ▪ "Me." ▪ "I do."
0	<p><i>Answer vague or obviously incorrect.</i></p>

Q. What is the medical problem?

A. A stroke

1	<p><i>Answer is an exact repetition, a correct synonym or definition.</i></p> <ul style="list-style-type: none"> ▪ "Stroke"
0	<p><i>Answer vague or obviously incorrect or doesn't meet criteria for 1 point.</i></p> <ul style="list-style-type: none"> ▪ "A heart attack."

Q. What problems are you having because of the stroke?

A. Makes it difficult for me to think and move.

2	<p><i>Answer demonstrates an ability to state at least two characteristics of the condition as an exact repetition, a correct synonym or definition.</i></p> <ul style="list-style-type: none"> ▪ 1 pt = "Think." ▪ 1 pt = "Move."
1	<p><i>States only one of exact answers above.</i></p> <ul style="list-style-type: none"> ▪ "Hard to move around."
0	<p><i>Answer is obviously incorrect or doesn't meet criteria for 1 or 2 pts (or none of exact answers above).</i></p> <ul style="list-style-type: none"> ▪ "I can't speak." ▪ "It would affect one side of the body." ▪ "I cannot function properly."

Q. Where are you living because of those problems and why?

A. Living in a nursing home because I need help to care for myself.

2	<p><i>Answer demonstrates an ability to state at least two characteristics of the condition as an exact repetition, a correct synonym or definition.</i></p> <ul style="list-style-type: none"> ▪ 1 pt = "Nursing Home." ▪ 1 pt = "Need help taking care of myself"
1	<p><i>States only one of exact answers above.</i></p> <ul style="list-style-type: none"> ▪ "I moved into a nursing home last year." ▪ "I can't take care of myself anymore."
0	<p><i>Answer is obviously incorrect or doesn't meet criteria for 1 or 2 pts (or none of exact answers above).</i></p> <ul style="list-style-type: none"> ▪ "If I had a stroke, I would want to live at home." ▪ "I'm living in a hospital because I had a stroke."

Q. What things can a person still enjoy in the nursing home?

A. Seeing family or friends and enjoying TV or music.

2	<p><i>Answer demonstrates an ability to state at least two characteristics of the condition as an exact repetition, a correct synonym or definition.</i></p> <ul style="list-style-type: none"> ▪ 1 pt = "Seeing family or friends." ▪ 1 pt = "Enjoying TV or music."
1	<p><i>States only one of exact answers above.</i></p> <ul style="list-style-type: none"> ▪ "Your wife still comes to visit." ▪ "You can still watch the football games on TV."
0	<p><i>Answer is obviously incorrect or doesn't meet criteria for 1 or 2 pts (or none of exact answers above).</i></p> <ul style="list-style-type: none"> ▪ "Contentment." ▪ "They feed you pretty well."

U2. UNDERSTANDING TREATMENT

Q. What does the doctor want you to decide?

A. If heart stops beating, whether to have CPR

2	<p><i>Answer demonstrates an ability to state two characteristics of the proposed treatment as an exact repetition, a correct synonym or definition.</i></p> <ul style="list-style-type: none"> ▪ 1 pt = "If heart stops beating." ▪ 1 pt = "Whether to have CPR."
1	<p><i>States only one of exact answers above.</i></p> <ul style="list-style-type: none"> ▪ "If I should be resuscitated." ▪ "What to do if my heart stops."
0	<p><i>Answer is obviously incorrect or doesn't meet criteria for 1 or 2 pts.</i></p> <ul style="list-style-type: none"> ▪ "Whether to pull the plug."

Q. What is involved in CPR?

A. Doctor or nurse pushes on chest; Blows air into mouth

2	<p><i>Answer demonstrates an ability to state at least two characteristics of the treatment as an exact repetition, a correct synonym or definition.</i></p> <ul style="list-style-type: none"> ▪ 1 pt = push on chest ▪ 1 pt = blow air into mouth
1	<p><i>States only one of exact answers above.</i></p> <ul style="list-style-type: none"> ▪ "They press on your chest." ▪ "The doctor breathes into your mouth."
0	<p><i>Answer is obviously incorrect or doesn't meet criteria for 1 or 2 pts (or none of exact answers above).</i></p> <ul style="list-style-type: none"> ▪ "They take your pulse." ▪ "They put their fingers in your mouth."

Q. What are the risks of CPR?

A. Brain damage; broken ribs

2	<p><i>Answer conveys the understanding of the concept of risk AND demonstrates an ability to state the risks associated with the medical decision-making situation portrayed in the scenario.</i></p> <ul style="list-style-type: none"> ▪ 1pt = "Brain damage." "Memory affected." "Lack of oxygen to brain." ▪ 1 pt = "Broken ribs." "Cracked ribs." "Damage to the chest."
1	<p><i>Answer conveys the understanding of the concept of risk BUT does not provide example(s) specifically relevant to the scenario or is vague.</i></p> <ul style="list-style-type: none"> ▪ "It may make it worse." ▪ "You may end up mentally and physically defective." ▪ "Bad things would happen."
0	<p><i>Answer does not convey understanding of concept of risk and does not provide examples relevant to the scenario or is obviously incorrect</i></p>

	<ul style="list-style-type: none"> ▪ “You could get a concussion.” ▪ “It might not work.”
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Q. What is the benefit of CPR?

A. Save life or keep heart/lungs going

1	<p><i>Answer conveys the understanding of the concept of benefit AND demonstrates an ability to state the benefits associated with the medical decision-making situation portrayed in the scenario.</i></p> <ul style="list-style-type: none"> ▪ “It will/may keep me alive.” “It may save my life.” ▪ “Keep heart and lungs going”
0	<p><i>Answer does not convey understanding of concept of risk and does not provide examples relevant to the scenario or is obviously incorrect.</i></p> <ul style="list-style-type: none"> ▪ “To me, there is no benefit.”

Q. What are the risks of not getting CPR?

A. Probably die

1	<p><i>Answer conveys the understanding of the concept of risk AND demonstrates an ability to state the risks associated with the medical decision-making situation portrayed in the scenario.</i></p> <ul style="list-style-type: none"> ▪ “Dying.” “Heart would not start up again and breathing would stop.”
0	<p><i>Answer does not convey understanding of concept of risk and does not provide examples relevant to the scenario or is obviously incorrect.</i></p> <ul style="list-style-type: none"> ▪ “You don’t have to worry about broken ribs.”

Appreciation as Distrust, General Rules

- 2 Acknowledges he/she has the disorder or potential benefit of treatment, or, disagrees but offers a reasonable explanation (based on experience, different medical opinion).**
- 1 Acknowledges possibility of disorder/treatment benefits but with doubt, or disagrees but offers reasons that are vague, ambivalent, or insufficiently justified**
- 0 Does not agree with explanation of disorder/treatment benefits, with reasoning that distorts reality, or relates symptoms to implausible circumstances**

A1. APPRECIATION I: DISTRUST**Q. If your heart stops beating, do you have any doubts that CPR might help you?**

2	<p><i>No, or Yes with reasonable explanation</i></p> <ul style="list-style-type: none"> ▪ “No, because you could get oxygen into your body.” ▪ “No, anything you might do to get things going (resuscitate) is worthwhile.” ▪ “No, it has been proven to work. If you give it soon enough, it will work.” ▪ “No, CPR is the one thing you can do to bring you back.” ▪ “Only if too much time has passed since my heart stopped beating. Otherwise it typically works.”
1	<p><i>No but questioning, or Yes with reasons that are vague, ambivalent, or insufficiently justified.</i></p> <ul style="list-style-type: none"> ▪ “Yes, I have many doubts. It is a question of time and response. I want certainty.” ▪ “Yes, the doctors might not do it right.”
0	<p><i>Yes with reasons that distort reality or relate symptoms to implausible circumstances</i></p> <ul style="list-style-type: none"> ▪ “Yes, I don’t want it. I see what they do in the ER.” ▪ “I would need the Heimlich instead.” ▪ “Yes. I don’t know what is wrong with me. I could stop breathing for a number of reasons.”

Q. Would you be concerned that the doctor might be trying to harm you?

2	<p><i>No, or Yes with reasonable explanation</i></p> <ul style="list-style-type: none"> ▪ “No. Doctors have a code of ethics.” ▪ “No. I think the doctor is there to help.” ▪ “No, because CPR is given as a standard procedure.”
1	<p><i>No but questioning, or Yes with reasons that are vague, ambivalent, or insufficiently justified.</i></p> <ul style="list-style-type: none"> ▪ “Yes, it is a slight possibility.” ▪ “No, but you can’t ever be 100% sure.”
0	<p><i>Yes with reasons that distort reality or relate symptoms to implausible circumstances.</i></p> <ul style="list-style-type: none"> ▪ “Yes, it is a little concerning because you don’t know what is going on when the doctor is pumping on you.” ▪ “Yes. They are only taking a chance to save you. I don’t want doctors cutting me up.”

C. EXPRESSING A CHOICE

Q. Remember that having a choice means being given the chance to do one of two or more things. What are your choices in this story?

A. To have CPR or not have CPR

2	<i>Answer demonstrates an ability to state both choices as an exact repetition, a correct synonym or definition.</i> <ul style="list-style-type: none"> ▪ “To have CPR or not.”
1	<i>Answer vague or only reflects one option.</i> <ul style="list-style-type: none"> ▪ “CPR or death.” ▪ “To have CPR.”
0	<i>Answer is obviously incorrect or doesn't meet criteria for 1 or 2 pts (or none of exact answers above).</i> <ul style="list-style-type: none"> ▪ “Live or die.”

Q. What would you tell the doctor you want them to do in this story if your heart stops beating?

A. [States choice.]

2	<i>States clear choice.</i> <ul style="list-style-type: none"> ▪ “Have CPR.” “Not have CPR.”
0	<i>Unable to state choice, or obviously incorrect (not specific to scenario)</i> <ul style="list-style-type: none"> ▪ “I choose to live everyday.”

R1. REASONING RATIONAL**Rational Reasons**

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

2	<p><i>Answer demonstrates ability to state at least two risks and/or benefits of the treatment as an exact repetition, a correct synonym or definition.</i></p> <ul style="list-style-type: none"> ▪ “I wouldn’t want to be a vegetable. I want my blood to be flowing again as soon as possible.” ▪ “I’ll risk broken ribs because CPR will possibly save me.”
1	<p><i>Answer vague (or only one of exact answer above).</i></p> <ul style="list-style-type: none"> ▪ “Whether I want to live or die.” ▪ “Longevity is a benefit. I just want to keep living.” ▪ “The risk is that you won’t continue to breathe.”
0	<p><i>Answer is obviously incorrect or doesn’t meet criteria for 1 or 2 pts (or none of exact answers above).</i></p> <ul style="list-style-type: none"> ▪ “You might recover on your own. Eventually we are all going to die.” ▪ “I learned from experience. This happened to my brother.”

Comparative Reasons

Q. Tell me why ___ seems better than ___.

2	<p><i>Offers at least one statement in the form of a comparison of at least two options (stated or clearly implied), with the comparison including a statement of at least one specific difference</i></p> <ul style="list-style-type: none"> ▪ “Being brain damaged when you’ve already have had a stroke is worse than being alive” ▪ “Because the alternative is to probably die.” ▪ “If I don’t have CPR, I’ll surely die. If I have CPR, I’ll probably live, but have brain damage.” ▪ “Not having CPR means I am going to die or I am dead. CPR gives me a chance to go on living.”
1	<p><i>Makes a comparison statement but does not include a statement of a specific consequence, i.e., says one is better than other without saying why</i></p> <ul style="list-style-type: none"> ▪ “The benefits outweigh the risks.” ▪ “CPR might be your last resort.”
0	<p><i>Makes no comparative statements, is obviously incorrect, OR makes comparison but reason is inconsistent with facts as presented in the vignette.</i></p> <ul style="list-style-type: none"> ▪ “I don’t want anybody blowing into my mouth. I can get their germs and get AIDS.”

R2. REASONING VALUES

Impact on Valued Activities and Abilities

Q. Looking at the list we made earlier, what are the ways in which [choice] could impact _____?

2	<p><i>Gives at least one specific consequence, or gives none with adequate justification</i></p> <ul style="list-style-type: none"> ▪ “I want to live by myself, but in this situation, I couldn’t do that without assistance.” ▪ “Having CPR will allow me to keep living.” ▪ “After CPR, I will probably not be able to think clearly about things.” ▪ “If I was paralyzed afterwards, I would probably have to rely on my wife to take care of me.” ▪ “I will have no worries because I will be dead.”
1	<p><i>Answer vague</i></p> <ul style="list-style-type: none"> ▪ “It might make it harder to do the things I’d like to do.”
0	<p><i>Gives no reasonable consequence (without justification), or states no impact when impact on choices is clear.</i></p> <ul style="list-style-type: none"> ▪ “I hope that I am not going to have another heart attack.” ▪ “If you don’t get any oxygen, you can end up with some pain.”

Impact on Valued Relationships

Q. How would your decision affect the people who care for you?

2	<p><i>Gives at least one specific consequence, or gives none with adequate justification</i></p> <ul style="list-style-type: none"> ▪ “They have to keep taking care of me if I live.” ▪ “They would want me to keep on having care.” ▪ “I would continue to have a relationship with my wife and my friends and be able to be me.”
1	<p><i>Answer vague</i></p> <ul style="list-style-type: none"> ▪ “There would be some confusion, but they would know what is best under the circumstances.” ▪ “I know they would be responsible.”
0	<p><i>Gives no reasonable consequence (without justification)</i></p> <ul style="list-style-type: none"> ▪ “It would be too much of a burden.” ▪ “I don’t think they would care.”

A2. APPRECIATION FORESIGHT

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

2	<p><i>For either choice, answer should reflect both documenting the choice AND informing others of the decision.</i></p> <ul style="list-style-type: none"> ▪ “You have to notify the people who will be taking care of you and sign papers.” ▪ “Write a directive and notify a doctor.”
1	<p><i>Answer vague (or only one of exact answer above)</i></p> <ul style="list-style-type: none"> ▪ “Let people know my decision.” ▪ “No, everything is done by the lawyer – signed, sealed, and copied.” ▪ “Just do the practical things you’re supposed to do.”
0	<p><i>States nothing or unrelated things to do</i></p> <ul style="list-style-type: none"> ▪ “Nothing. CPR is not one of those decisions other people have to make for you.” ▪ “Keep an eye on my blood pressure.” ▪ “Make sure I get a good doctor.”

Q. If your heart stops beating, do you believe you might get better without CPR?

2	<p><i>No, or Yes with reasonable explanation</i></p> <ul style="list-style-type: none"> ▪ “No. If my heart stops beating I am dead.” ▪ “No, because if your heart stops beating, you can get brain damage pretty quickly.”
1	<p><i>No but questioning, or Yes with reasons that are vague, ambivalent, or insufficiently justified.</i></p> <ul style="list-style-type: none"> ▪ “Maybe. Anything can happen but it might not work out too well.” ▪ “I doubt it, but it is possible. It has happened before.”
0	<p><i>Yes with reasons that distort reality or relate symptoms to implausible circumstances.</i></p> <ul style="list-style-type: none"> ▪ “Yes, there is an 80% chance of coming out of it.” ▪ “I don’t need CPR because I have a pacemaker.”

Vignette #3: Leg Ulcer**Understanding, General Rules**

- 2** **Recalls/restates content fairly clearly. Answer an exact repetition, a correct synonym or definition**
1 **Recalls/restates content but describes in a way that renders understanding uncertain. Answer is vague or broad. Or Answer contains some content but lacks other content.**
0 **Answer is obviously incorrect or doesn't meet criteria for 1 or 2 points**

U1. UNDERSTANDING: DISORDER

Q. Who has the medical problem?

A. Me or I do

1	<i>Answer is an exact repetition, a correct synonym or definition.</i> ▪ "Me." "I do."
0	<i>Answer vague or obviously incorrect.</i>

Q. What is the medical problem?

A. Non-healing toe ulcer

1	<i>Answer is an exact repetition, a correct synonym or definition.</i> ▪ "Toe [required] ulcer, wound, open area."
0	<i>Answer vague or obviously incorrect or doesn't meet criteria for 1 point.</i> ▪ "Sore." "Tumor."

Q. What is a non-healing toe ulcer?

A. An infected open sore that does not respond to medication.

2	<i>Answer demonstrates an ability to state at least two characteristics of the condition as an exact repetition, a correct synonym or definition.</i> ▪ 1 pt = "Open sore." "Open area." "Open ulcer." ▪ 1 pt = "Does not respond to medication." "Not treatable."
1	<i>Answer vague (or only one of exact answers above).</i> ▪ "Infection." "Lesion."
0	<i>Answer is obviously incorrect or none of exact answers above</i> ▪ "Something that hurts."

Q. What causes a non-healing toe ulcer?

A. Lack of blood supply from legs to feet

2	<i>Answer is an exact repetition, a correct synonym or definition.</i> ▪ 1 pt = "Lack of blood supply." or any mention of blood, blood flow, or circulation. ▪ 1 pt = "Legs to feet." "To lower leg." "To the toe."
1	<i>Answer vague.</i> ▪ "To the area." "To the leg."
0	<i>Answer is obviously incorrect or doesn't meet criteria for 1 or 2 pts.</i> ▪ "Down there."

Q. What happens if it is not treated?

A. Infection may spread and lead to death

2	<i>Answer demonstrates an ability to state at least two characteristics of the condition as an exact repetition, a correct synonym or definition.</i> ▪ 1 pt = "May spread" ▪ 1 pt = "Lead to death"
1	<i>Answer vague (or only one of exact answers above).</i> ▪ "Get gangrenous."
0	<i>Answer is obviously incorrect or none of exact answers above.</i> ▪ "Lose toe."

U2. UNDERSTANDING: TREATMENT 1

Q. What is the first treatment for the toe ulcer?

A. Surgery on an artery in your leg

2	<p><i>Answer is an exact repetition, a correct synonym or definition</i></p> <ul style="list-style-type: none"> ▪ 1 pt = Surgery or synonym (e.g. operation) ▪ 1 pt = Artery in your leg or similar word – vein, blood supply or leg
1	<i>Answer vague or states only one of exact answers above.</i>
0	<i>Answer is obviously incorrect or none of exact answers above.</i>

Q. What is involved in the surgery and recovery?

A. The surgery involves an incision all the way down the leg to insert a new artery.

2	<p><i>Answer demonstrates an ability to state two characteristics of the treatment as an exact repetition, a correct synonym or definition.</i></p> <ul style="list-style-type: none"> ▪ 1 pt = Incision all the way down leg ▪ 1 pt = Insert new artery or similar word – vascular, vessels
1	<i>States only one of exact answers above.</i>
0	<i>Answer is obviously incorrect or none of exact answers above.</i>

Q. What are the benefits of surgery?

A. Could increase blood supply to the foot and save your toe.

2	<p><i>Answer conveys the understanding of the concept of benefit AND demonstrates an ability to state the benefits associated with the medical decision-making situation portrayed in the scenario.</i></p> <ul style="list-style-type: none"> ▪ 1 pt = Increase blood supply to foot or words describing blood and circulation/circulatory benefit. ▪ 1 pt = Save your toe, heal toe, would not lose toe, blood would get to toe, toe would be healed.
1	<p><i>Answer conveys the understanding of the concept of benefit BUT does not provide example(s) specifically relevant to the scenario or is vague.</i></p> <ul style="list-style-type: none"> ▪ “Cure it.” ▪ “Take care of ulcer on toe.” ▪ “Save leg.”
0	<p><i>Answer does not convey understanding of concept of benefit and does not provide examples relevant to the scenario or is obviously incorrect.</i></p> <ul style="list-style-type: none"> ▪ “The infection could still spread.”

Q. What are the risks of surgery?

A. There is a 5% chance of dying during surgery; will need help for six weeks while recover.

2	<p><i>Answer conveys the understanding of the concept of risk AND demonstrates an ability to state the benefits associated with the medical decision-making situation portrayed in the scenario.</i></p> <ul style="list-style-type: none"> ▪ 1 pt = Need help for six weeks or a statement conveying a lengthy recovery. ▪ 1 pt = Risk of dying (5% not required) or any words specific to the risk of death.
1	<p><i>Answer conveys the understanding of the concept of risk BUT does not provide example(s) specifically relevant to the scenario or is vague.</i></p> <ul style="list-style-type: none"> ▪ “May not solve the problem.”
0	<p><i>Answer does convey understanding of concept of risk and does not provide examples relevant to the scenario or is obviously incorrect.</i></p> <ul style="list-style-type: none"> ▪ “Lose foot.”

Appreciation as Distrust, General Rules

- 2 Acknowledges he/she has the disorder or potential benefit of treatment, or, disagrees but offers a reasonable explanation (based on experience, different medical opinion).**
- 1 Acknowledges possibility of disorder/treatment benefits but with doubt, or disagrees but offers reasons that are vague, ambivalent, or insufficiently justified.**
- 0 Does not agree with explanation of disorder/treatment benefits, with reasoning that distorts reality, or relates symptoms to implausible circumstances.**

A1. APPRECIATION DISTRUST

Q. Do you have any doubts that surgery might help you?

2	<p><i>No, or Yes with reasonable explanation</i></p> <ul style="list-style-type: none"> ▪ “No. I am convinced if the diagnosis is properly made, the risk is low, so it is worth it to have the surgery.”
1	<p><i>No but questioning, or Yes with reasons that are vague, ambivalent, or insufficiently justified.</i></p> <ul style="list-style-type: none"> ▪ “No, because how else are you going to do it?” ▪ “Maybe. If the doctor told me that something was bad, I would suggest going to a specialist and following what he would say.” ▪ “Yes. You are taking a risk and it could go either way.” ▪ “Yes. You said “could” or “would” improve.”
0	<p><i>Yes with reasons that distort reality or relate symptoms to implausible circumstances.</i></p> <ul style="list-style-type: none"> ▪ “Yes. I already had four screws in my legs, but there is nothing wrong with my toes.”

Q. Would you be concerned that the doctor might be trying to harm you?

2	<p><i>No, or Yes with reasonable explanation</i></p> <ul style="list-style-type: none"> ▪ “No, I have faith in doctors. They are trained. If I thought he was going to harm me, I would go to another doctor.” ▪ “No, it’s against their creed to harm you.” ▪ “No. I just don’t have any concerns.” ▪ “No, he is a professional.” ▪ “Yes, because I had a surgery go wrong before. I don’t think he would do so on purpose, though.”
1	<p><i>No but questioning, or Yes with reasons that are vague, ambivalent, or insufficiently justified.</i></p> <ul style="list-style-type: none"> ▪ “Yes. You never know for sure.” ▪ “Yes, because I have a 5% risk of death. I don’t want surgery.” ▪ “Maybe, but he has to worry about his malpractice insurance going up if I die.”
0	<p><i>Yes with reasons that distort reality or relate symptoms to implausible circumstances.</i></p> <ul style="list-style-type: none"> ▪ “It all depends on who the nurse is during the surgery.” ▪ “Doctors don’t care about patients, they only care about themselves.”

UNDERSTANDING: TREATMENT 2

Q. What is the second treatment for the toe ulcer?

A. Big toe amputated

2	<p><i>Answer is an exact repetition, a correct synonym or definition.</i></p> <ul style="list-style-type: none"> ▪ 1 pt = Toe (required). ▪ 1 pt = Amputated or words to describe the same cut off, removed.
1	<p><i>Answer vague (or only one of exact answer above).</i></p> <ul style="list-style-type: none"> ▪ "Toe operated on."
0	<p><i>Answer is obviously incorrect or none of exact answers above.</i></p>

Q. What is involved in the amputation and recovery?

A. A surgeon cuts off toe. The amputation and recover are quick.

2	<p><i>Answer demonstrates an ability to state two characteristics of the treatment as an exact repetition, a correct synonym or definition.</i></p> <ul style="list-style-type: none"> ▪ 1 pt = Cuts off toe. ▪ 1 pt = Quick (surgery or recovery).
1	<p><i>Answer vague (or only one of exact answer above).</i></p>
0	<p><i>Answer is obviously incorrect or none of exact answers above.</i></p>

Q. What are the benefits of amputation?

A. Get rid of infected tissue without major surgery

2	<p><i>Answer conveys the understanding of the concept of benefit AND demonstrates an ability to state the benefits associated with the medical decision-making situation portrayed in the scenario.</i></p> <ul style="list-style-type: none"> ▪ 1 pt = Get rid of infected tissue ▪ 1 pt = Without major surgery
1	<p><i>Answer conveys the understanding of the concept of benefit BUT does not provide example(s) specifically relevant to the scenario or is vague.</i></p> <ul style="list-style-type: none"> ▪ "Get rid of the problem."
0	<p><i>Answer does not convey understanding of concept of benefit and does not provide examples relevant to the scenario or is obviously incorrect.</i></p> <ul style="list-style-type: none"> ▪ "No death."

Q. What are the risks of amputation?

A. Using a cane and having difficulty with balance.

2	<p><i>Answer conveys the understanding of the concept of risk AND demonstrates an ability to state the risks associated with the medical decision-making situation portrayed in the scenario.</i></p> <ul style="list-style-type: none"> ▪ 1 pt = Having to use a cane. ▪ 1 pt = Difficulty with balance.
1	<p><i>Answer conveys the understanding of the concept of risk BUT does not provide example(s) specifically relevant to the scenario or is vague.</i></p> <ul style="list-style-type: none"> ▪ "Lose your balance." ▪ "Need to learn to walk again."
0	<p><i>Answer does not convey understanding of concept of risk and does not provide examples relevant to the scenario or is obviously incorrect.</i></p> <ul style="list-style-type: none"> ▪ "I know other people who have had it done and they are ok." ▪ "You could run into complications with your heart."

C. EXPRESSING A CHOICE

Q. Remember that having a choice means being given the chance to do one of two or more things. What are your choices in this story?

A. Surgery on leg or amputation.

2	<i>Answer demonstrates an ability to state both choices as an exact repetition, a correct synonym or definition. 1 pt = Surgery on leg 1 pt = Amputation</i>
1	<i>Answer reflects only one option. ▪ “Do the surgery.”</i>
0	<i>Is unable to name either choice.</i>

Q. What would you do about the toe ulcer?

A. [States choice]

2	<i>States clear choice. ▪ “Have surgery.” ▪ “Lose the toe.”</i>
0	<i>Unable to state choice, ambivalent, vague, or obviously incorrect (not specific to scenario) ▪ “I want to do what’s best for my health.”</i>

R1. REASONING RATIONAL**Rational Reasons**63. Q. **What risks and benefits did you consider when making that decision?**

2	<p><i>Answer demonstrates ability to state at least two risks and/or benefits of the treatment as an exact repetition, a correct synonym or definition.</i></p> <p><i>1 pt for any of the following:</i></p> <ul style="list-style-type: none"> ○ “Surgery.” ○ “Increased blood supply.” ○ “Saves toe.” ○ “Might not work.” ○ “Might die.” ○ “Amputation gets rid of infected tissue.” ○ “You go without major surgery.” ○ “Have difficulty with balance afterwards.” <p><i>Sample 2 pt answers:</i></p> <ul style="list-style-type: none"> ▪ “Getting rid of infected tissue and not having major surgery.” ▪ “Chances are I could die and I would have a long recovery.”
1	<p><i>Answer vague (or only one of exact answer above).</i></p> <ul style="list-style-type: none"> ▪ “The smaller surgery has less risk of dying.”
0	<p><i>Answer is obviously incorrect or doesn’t meet criteria for 1 or 2 pts (or none of exact answers above).</i></p> <ul style="list-style-type: none"> ▪ “It may not work out the way you like it.” ▪ “The risks and benefits are about the same for both of them, in my opinion.”

Comparative ReasonsQ. **Tell me why _____ it seems better than _____.**

2	<p><i>Offers at least one statement in the form of a comparison of at least two options (stated or clearly implied), with the comparison including a statement of at least one specific difference</i></p> <ul style="list-style-type: none"> ▪ “Amputation is quicker and I’d get back to normal soon.” ▪ “With the amputation, there is no guarantee that you have solved the problem of the blood supply.” ▪ “Because I will still have an option to do any work, save my toe, and have no need for a cane.” ▪ “Moving the artery is a long shot. Since the infection might still be there, it seems best just to get rid of it.” ▪ “To me, when replacing the whole artery, the risks in surgery are more than just cutting the toe off. I could live with using a cane.”
1	<p><i>Makes a comparison statement but does not include a statement of a specific consequence, i.e., says one is better than other without saying why. Offers vague reasons why.</i></p> <ul style="list-style-type: none"> ▪ “That’s how you walk – with your toes. I can’t lose them.” ▪ “Amputation is better than surgery for me.”
0	<p><i>Makes no comparative statements, is obviously incorrect, OR makes comparison but reason is inconsistent with facts as presented in the vignette.</i></p> <ul style="list-style-type: none"> ▪ “I would just be following doctor’s orders.”

R1. REASONING VALUES

Impact of Choices on Valued Activities and Abilities

Q. Looking at the list we made earlier, what are the ways in which [choice] could impact ____?

2	<p><i>Gives at least one specific consequence, or gives none with adequate justification</i></p> <ul style="list-style-type: none"> ▪ “At first, you are confined to a hospital for a week, and then you have loving care at home.” ▪ “I would be able to do the three things I listed if I didn’t use a cane.” ▪ “It will not impact me. I can swim and garden without a toe.”
1	<p><i>Answer vague</i></p> <ul style="list-style-type: none"> ▪ “Outside of being laid up for six weeks, I don’t see any major problem.” ▪ “After they cut your toe, you can still feel it a bit.”
0	<p><i>Gives no reasonable consequence (without justification), or states no impact when impact on choices is clear.</i></p> <ul style="list-style-type: none"> ▪ “I don’t know how they would be impacted.”

Impact of Choices on Valued Relationships

Q. How would your decision affect the people who care for you?

2	<p><i>Gives at least one specific consequence, or gives none with adequate justification.</i></p> <ul style="list-style-type: none"> ▪ “They will have to stay at home more often. I don’t think it will impact them any more than that.” ▪ “They have to help me a lot during the six weeks.” ▪ “It really wouldn’t impact my children because they don’t live nearby. My wife has died. I would have to fend for myself.”
1	<p><i>Answer vague.</i></p> <ul style="list-style-type: none"> ▪ “It will affect them a little bit. They don’t like to take care of me.” ▪ “They will be very concerned.”
0	<p><i>Gives no reasonable consequence (without justification)</i></p> <ul style="list-style-type: none"> ▪ “They would lose their job.” ▪ “It is a personal decision that only I make.”

A2. APPRECIATION FORESIGHT**Q. Since you decided to [choice] is there anything you need to do to plan for it?**

2	<p><i>Gives at least two things to do.</i> Give 1 pt for any of the following:</p> <ul style="list-style-type: none"> ▪ If surgery: Plan for long recovery; plan for event of possible death. <ul style="list-style-type: none"> ○ “Make sure I have a relative there to help me while I recover. I would have plenty of food and movies and a phone by the sofa when I come home.” ○ “I’d keep my family informed about my choices and what to do if I didn’t wake up. Maybe they could talk to the doctor too, so they know what I will need after the surgery.” ▪ If amputation: Plan for getting a cane; learning how to walk; difficulties with balance. Any response indicating putting affairs in order is also acceptable. <ul style="list-style-type: none"> ○ “Mentally get in a frame of mind where amputation is better and talk it over with friends and family.” ○ “They give you a cane and you have to train to have more balance.” ○ “Even though it is a small surgery, I would like to make sure my will is in order. I would also make sure my personal problems at home are taken care of.”
1	<p><i>Answer vague (or only one of exact answer above).</i></p> <ul style="list-style-type: none"> ▪ “Just follow the doctor’s orders and cooperate with them.” ▪ “Notify the hospital staff.”
0	<p><i>States nothing to do</i></p> <ul style="list-style-type: none"> ▪ “No. You have the surgery as an outpatient.” ▪ “No. That would be a medical decision. Once you decide, that’s all you have to do.”

Q. Do you believe you might get better without treatment?

2	<p><i>No, or Yes with reasonable explanation</i></p> <ul style="list-style-type: none"> ▪ “No, not necessarily, because my blood flow is very bad.” ▪ “No, the infection is still there, and it usually gets worse if not treated.” ▪ “No. I doubt it because the doctor says it won’t.” ▪ “No, I am told I have a non-curable, non-healing toe.”
1	<p><i>No but questioning, or Yes with reasons that are vague, ambivalent, or insufficiently justified.</i></p> <ul style="list-style-type: none"> ▪ “Maybe. Things sometimes surprise you.”
0	<p><i>Yes with reasons that distort reality or relate symptoms to implausible circumstances.</i></p> <ul style="list-style-type: none"> ▪ “Yes. I believe in miracles. I’ve been cured before.” ▪ “Depends on the treatment. I know about certain creams that would help it.”

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