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# Competency to Decide on Treatment and Research: MacArthur and Beyond

ELYN R. SAKS\*  
STEPHEN H. BEHNKE\*\*

*Every competent adult has the right to informed consent.* These words carry with them the weight of a rich, yet troubled, history. They state a maxim of late 20th century bioethics, a maxim that was borne, in part, of horrific abuses during a holocaust without parallel in human history. While today the concept of a right to informed consent is firmly ensconced in the culture of United States medicine, much work remains to be done to pour content into key elements of this right: How can it be determined when an adult's consent is "competent"? When is consent truly "informed"? And what exactly constitutes "consent"?

This article will discuss the competency of psychiatric patients in the contexts of treatment and research. Our hope is to identify areas where further normative discussion about instruments designed to assess competence—the MacArthur instruments being the premier example—will be fruitful. We first argue that any instrument designed to aid in assessing competency to consent to treatment necessarily implicates normative considerations, that is, entails identifying and balancing values. We then review the MacArthur instruments to explore their normative underpinnings. Next, we examine how the MacArthur investigators have balanced three values—autonomy, paternalism, and

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\* Orrin B. Evans Professor of Law, Psychiatry and the Behavioral Sciences, University of Southern California Law Center.

\*\* Faculty Fellow in Ethics, Program in Ethics & the Professions, Harvard University. Dr. Behnke has recently been appointed Director, Program in the Practice of Scientific Integrity, Division of Medical Ethics, Harvard Medical School.

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nondiscrimination against the mentally ill—and suggest different ways of balancing these values against one another when doing so seems appropriate. Finally, we ask what additional normative considerations arise in the context of psychiatric research.

## I. NORMATIVE JUDGMENTS IN CREATING INSTRUMENTS DESIGNED TO AID IN ASSESSING COMPETENCY

Adopting an instrument to aid in assessing competency requires careful normative analysis.<sup>1</sup> A critical issue is how to strike the balance between autonomy and paternalism. While bioethicists have moved beyond this dichotomy in many areas, the tension between autonomy and paternalism remains central to the assessment of competency. Indeed, standards for competency are the lines drawn between those who may exercise autonomous choices and those on behalf of whom—*over* whom—decisions will be made.

Striking the balance between autonomy and paternalism by holding that competent patients alone have the right to exercise autonomous choices is of little help. Such a tautological statement merely restates the problem: competent patients are free to make choices, while incompetent patients are not and must allow others to make choices on their behalf. One challenge in defining competency is therefore to show *where* autonomy ends and paternalism begins. Perhaps the most subtle and even important part of defining competency requires that we decide how much latitude to give the decision maker in selecting a method of decision making. Are intuitive methods adequate? Must all alternatives be compared and contrasted? How much scope will the decision maker have to select a particular version of the truth, even if that version is idiosyncratic and unpopular?

To begin our search for a definition of competency, we attempt to identify all the values at play. First, we want to protect the vulnerable who are unable to make decisions for themselves. We call this value

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1. Since the writing of this article, the MacArthur researchers, Thomas Grisso and Paul Appelbaum, have published a book that bears on this critique. THOMAS GRISSE & PAUL S. APPELBAUM, *ASSESSING COMPETENCE TO CONSENT TO TREATMENT* (1998) [hereinafter *ASSESSING COMPETENCE*]. In this book, the researchers lay out the kind of normative analysis that an individual must undertake in using the instrument they have designed to assess competency in a treatment setting. See *infra* note 5. Grisso and Appelbaum point out that a competency judgment must balance autonomy and paternalism, and that the balance may change depending upon the consequences of deciding one way or the other. This paper attempts to contribute to the discussion over the values at stake in assessing competency.

“paternalism.” Paternalism requires that we ask what abilities are essential for making decisions, so that we can determine when those abilities are lacking. Second, we want to protect the right to make choices, even when those choices are unconventional and stray from commonly held beliefs, views, and desires. We call this value “autonomy.” Finally, we must be mindful what mental health professionals—particularly psychoanalysts, have discovered—namely, that irrationality permeates decision making. As examples, people commonly misunderstand statistics, overvalue vivid memories, and form distorted beliefs about their doctors.<sup>2</sup> Our knowledge of the pervasive irrationality that governs decision making—indeed, that governs all human activities—serves as reason for extreme caution. We must be careful not to label as incompetent individuals with a mental illness who suffer no more irrationality in the relevant regard than many, if not most, other people. Not to heed this caution is to risk stigmatizing the mentally ill. Here is our third value, “nondiscrimination.”

Our definition of competency must be founded upon a clear conception of how autonomy, paternalism, and nondiscrimination work together and are weighed against one another. Clarity about what values are at play and how those values work together is the watch word. Concretely, we must first justify *which* abilities competency requires and what *level* of these abilities must be present. Thus, the researcher must ask: are *these* abilities, with *this* level of performance, really necessary, and if so, why? Conversely, might an ability be desirable, but inessential, much as speaking a foreign language with a good accent is not essential to basic communication? Deeming a particular skill helpful is also not necessarily definitive to making a decision. Other questions arise: Will requiring this skill for competency tread too greatly on autonomy? And if the absence or impairment of a skill is widespread, do we risk discrimination by requiring this skill only of the mentally ill? In short, defining competency is a thoroughly normative endeavor.<sup>3</sup>

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2. See, e.g., SIGMUND FREUD, *PSYCHOPATHOLOGY OF EVERYDAY LIFE* (1901); JAY KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT* (1984); Daniel Kahneman, *New Challenges to the Rationality Assumption*, 150 *J. INSTITUTIONAL & THEORETICAL ECON.* 18 (1994); Donald A. Redelmeier et al., *Understanding Patients' Decisions: Cognitive and Emotional Perspectives*, 270 *JAMA* 72 (1993); Amos Tversky & Daniel Kahneman, *Rational Choice and the Framing of Decisions*, 59 *J. BUS.* S251 (1986).

3. We do not mean to suggest that choosing a competency standard is *completely* normative, just that it is *in large part* normative. Choosing such a standard also depends on empirical findings—such as what impairments lead to substandard decisions, what

## II. THE MACARTHUR INSTRUMENTS

The premier work on competency to make treatment and research decisions has been produced by the MacArthur network on law and mental health.<sup>4</sup> The work of the MacArthur researchers, in particular Paul Appelbaum and Thomas Grisso, has been impressive indeed. The MacArthur researchers have developed three research instruments and one instrument designed for use in direct care settings. The instruments have achieved high reliability, can be administered with relative ease, and have been studied in interesting and informative ways.<sup>5</sup> The

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abilities people actually use when they are deciding, and how psychiatric impairments can affect the ability to make a decision.

4. The literature contains studies of only a few other treatment capacity/competency instruments. See, e.g., C. Dennis Barton, Jr. et al., *Clinicians' Judgment of Capacity of Nursing Home Patients to Give Informed Consent*, 47 PSYCHIATRIC SERVICES 956 (1996) (using Hopkins Competency Assessment Test [HCAT]); Jeffrey S. Janofsky et al., *The Hopkins Competency Assessment Test: A Brief Method for Evaluating Patients' Capacity to Give Informed Consent*, 43 HOSP. & COMMUNITY PSYCHIATRY 132 (1992) (utilizing the HCAT); Gary N. Sales, *Assessing Competency*, 43 HOSP. & COMMUNITY PSYCHIATRY 646 (1992) (discussing article on HCAT); Michael Lavin, *Assessing Competency*, 43 HOSP. & COMMUNITY PSYCHIATRY 646-47 (1992) (discussing same); Jay Englehart, *Assessing Competency*, 43 HOSP. & COMMUNITY PSYCHIATRY 647 (1992) (discussing same); Graham Bean et al., *The Assessment of Competence to Make a Treatment Decision: An Empirical Approach*, 41 CAN. J. PSYCHIATRY 85 (1996) (evaluating the Competency Interview Schedule [CIS]); Graham Bean et al., *The Psychometric Properties of the Competency Interview Schedule*, 39 CAN. J. PSYCHIATRY 368 (1994) (evaluating CIS); Daniel C. Marson et al., *Cognitive Models That Predict Physician Judgments of Capacity to Consent in Mild Alzheimer's Disease*, 45 J. AM. GERIATRICS SOC'Y 458 (1997) (testing of Alzheimer patients based on vignette procedure intended to identify incompetency based on Roth, Meisel, and Lidz' discussion of different standards in *Tests of Competency to Consent to Treatment*, 134 AM. J. PSYCHIATRY 279 (1977)); Daniel C. Marson et al., *Neuropsychologic Predictors of Competency in Alzheimer's Disease Using a Rational Reasons Legal Standard*, 52 ARCHIVES OF NEUROLOGY 955 (1995) (using same instrument); Daniel C. Marson et al., *Toward a Neurologic Model of Competency: Cognitive Predictors of Capacity to Consent in Alzheimer's Disease Using Three Different Legal Standards*, 46 NEUROLOGY 666 (1996) (using same instrument); Daniel C. Marson et al., *Determining the Competency of Alzheimer Patients to Consent to Treatment and Research*, 8 ALZHEIMER DISEASE & ASSOCIATED DISORDERS 5 (Supp. 1994) (discussing the same instrument); Atsuko Tomoda et al., *Validity and Reliability of Structured Interview for Competency Incompetency Assessment Testing and Ranking Inventory*, 53 J. CLINICAL PSYCHOL. 443 (1997) (evaluating Structured Interview for Competency and Incompetency Assessment Testing and Ranking Inventory [SICIATRI]). The MacArthur instruments appear to be the most carefully constructed, best studied, and most discussed instruments in the literature.

5. The MacArthur researchers have written a number of articles describing the development of the three MacArthur research instruments and the treatment competence instrument (the MacCAT-T), as well as their application to patient populations and

MacArthur instruments will undoubtedly be the “gold-standard” for assessing competency for many years to come.

The three MacArthur research instruments are: (1) the Understanding Treatment Disclosures instrument (UTD), which measures understanding;<sup>6</sup> (2) the Perceptions of Disorder instrument (POD),

matched controls. See, e.g., Paul S. Appelbaum & Thomas Grisso, *The MacArthur Treatment Competence Study. I: Mental Illness and Competence to Consent to Treatment*, 19 LAW & HUM. BEHAV. 105 (1995); Thomas Grisso et al., *The MacArthur Treatment Competence Study. II: Measures of Abilities Related to Competence to Consent to Treatment*, 19 LAW & HUM. BEHAV. 127 (1995) [hereinafter *MacArthur I*]; Thomas Grisso & Paul S. Appelbaum, *The MacArthur Treatment Competence Study. III: Abilities of Patients to Consent to Psychiatric and Medical Treatments*, 19 LAW AND HUM. BEHAV. 149 (1995); Thomas Grisso & Paul S. Appelbaum, *Comparison of Standards for Assessing Patients' Capacities to Make Treatment Decisions*, 152 AM. J. PSYCHIATRY 1033 (1995); Jessica Wilen Berg et al., *Constructing Competence: Formulating Standards of Legal Competence to Make Medical Decisions*, 48 RUTGERS L. REV. 345 (1996) [hereinafter *Constructing Competence*]; Paul S. Appelbaum & Thomas Grisso, *Capacities of Hospitalized, Medically Ill Patients to Consent to Treatment*, 38 PSYCHOSOMATICS 119 (1997) [hereinafter *Hospitalized*]. They have also recently published a book on the MacCAT-T. See ASSESSING COMPETENCE, *supra* note 1. They have an article in press on the application of their instruments to the research context. See Jessica Wilen Berg & Paul S. Appelbaum, *Subjects' Capacity to Consent to Neurobiological Research*, in ETHICAL ISSUES IN PSYCHIATRIC RESEARCH: A RESEARCH MANUAL ON HUMAN SUBJECTS PROTECTION (Harold Alan Pincus et al. eds., forthcoming 2000) [hereinafter *Subjects' Capacity*]. Finally, considerable literature discusses the MacArthur instruments, most notably the articles in volume 2 of PSYCHOLOGY, PUBLIC POLICY, AND LAW EXPLORING A SPECIAL THEME: A CRITICAL EXAMINATION OF THE MACARTHUR TREATMENT COMPETENCE STUDY: METHODOLOGICAL ISSUES, LEGAL IMPLICATIONS, AND FUTURE DIRECTIONS. See 2 PSYCHOL. PUB. POL'Y & L. (1996).

6. The best way to understand the MacArthur instruments is to look at their manuals. For the UTD, see THOMAS GRISSO & PAUL S. APPELBAUM, MANUAL FOR UNDERSTANDING TREATMENT DISCLOSURES (1992) (unpublished manual available from authors). The UTD measures the subject's understanding of treatment disclosures about the illness he or she suffers from and its treatment. Form disclosures were devised for schizophrenia, depression, and ischemic heart disease (angina). Each disclosure, using language understandable at the junior high level, consists of five simple paragraphs briefly describing the illness and its treatment.

The first paragraph focuses on the illness itself, as well as on two common symptoms of the illness (“Schizophrenia is a mental disorder. People with schizophrenia often have unpleasant experiences, called symptoms. For example, they . . . may hear voices talking about what they are doing, even when there are no other people around.”). *Id.* at 24. The second paragraph discusses treatment, how it is administered, and what is required of the patient for treatment to be effective (“Fortunately, schizophrenia can be treated with medicine. . . . But if patients stop taking this medicine, their symptoms may come back.”). *Id.* The third examines the potential benefits of the treatment (“The medicines used to treat schizophrenia help many patients to think more clearly. They often stop the

which measures one's appreciation of disclosures about illness and treatment as they apply to one's own situation;<sup>7</sup> and (3) the Thinking

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frightening voices that some patients with schizophrenia hear.”). *Id.* The fourth paragraph notes the potential side-effects of the treatment (“[T]he medicine might make patients restless or cause their muscles to tighten up.”). *Id.* The fifth paragraph considers alternatives, benefits of the alternatives, and potential problems with the alternatives (“There is also psychotherapy [to help treat schizophrenia]. . . . This talking therapy may help patients better understand themselves and their feelings. But psychotherapy alone does not usually help with schizophrenia by itself. . . . [it] is most helpful when the patient is also taking medicine.”). *Id.*

The UTD is administered in three forms. First, the patient is read the entire disclosure and asked to paraphrase what has been said (with questions prompting him if need be). Second, the patient is then read each element of the disclosure format again and asked, after each element, whether a statement read is “the same as or different from” what has been said.

Patients receive points depending on how much they have remembered and (presumably) understood. For example, if two symptoms of schizophrenia have been disclosed, a patient will receive a full score on that issue if he or she repeats or paraphrases those two symptoms. The patient will also receive a maximum score (but no additional points) if he or she includes those two but adds others that were not disclosed to him or her. The patient will receive no credit if he or she remembers none of the symptoms or if he or she brings up other symptoms—even if they are bona fide symptoms of schizophrenia—that he or she did not hear in the disclosure and he or she fails to name disclosed items.

7. The POD measures people's appreciation of their illness and its treatment. The POD requires that one apply general information to one's own situation. There are two subtests, the Non-Acknowledgment of Disorder (NOD) subtest and the Non-Acknowledgment of Treatment Potential (NOT) subtest. The NOD measures the patient's failure to acknowledge his or her diagnosis, the severity of his or her condition, or the symptoms he or she has been demonstrating. “Objective” measures of these three are provided by the diagnosis given in the patient's medical chart, the severity of his or her symptoms as measured by the Brief Psychiatric Rating Scale, and the symptoms recently reported in his or her medical chart.

The NOT measures patients' failure to acknowledge the potential value of treatment for their illnesses even when successful treatment is likely. It focuses on the extent to which patients believe (1) any treatment might be of benefit to them, (2) medication specifically might benefit them, and (3) the course of improvement is likely to be lessened absent treatment. If patients fail to acknowledge the potential benefits of treatment, they are provided a hypothetical premise that logically nullifies their reasoning (*e.g.*, “imagine that a doctor tells you that there is a medication that has been shown in research to help 90% of people with your problem, *even people who had not gotten better with any other medication*). Non-acknowledgment is scored only if the patient fails to acknowledge the potential benefits of treatment under the hypothetical condition. The NOT does not assess whether patients would agree to the medication—just whether they believe it might be of possible benefit.

There are three additional elements of the POD that have been included for exploratory reasons only. These items assess patients' acknowledgment of potential side-effects of medication generally, their perceptions of the beneficence of the hospital staff, and their perceptions of their own need for hospitalization.

Rationally About Treatment instrument (TRAT), which measures one's reasoning skills as one decides about a hypothetical treatment dilemma based on one's own condition.<sup>8</sup> A subset of the TRAT measures one's

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See Paul S. Appelbaum & Thomas Grisso, *Manual for Perceptions of Disorder (POD)* (1992) (unpublished manual available from authors).

8. The TRAT measures patients' ability to think rationally about treatment. The instrument gives a vignette including information about a disorder, various treatment alternatives, and their probable risks and benefits. It then asks the subject to recommend one of the treatments to a friend with the relevant illness and to describe the reasons for the selection. The patient's reasoning is scored for various cognitive activities that are considered important to making a decision. A second set of procedures examines more formal cognitive functions relevant to decision making.

The cognitive functions identified are Seeking Information (tendency to seek information beyond what is provided), Consequential Thinking (consideration of consequences of treatment alternatives), Comparative Thinking (simultaneous processing of information about two treatment alternatives, such that they are considered in relation to each other), Complex Thinking (attention to the full range of treatment alternatives), and Generating Consequences (generation of potential real-life consequences of the liabilities described in the informed consent disclosure, such as how a side-effect of medication might affect job performance). The TRAT measures three additional cognitive functions independent of the vignette: Weighting Consequences (tendency for consistent application of preferences), Transitive Thinking (assessment of relative quantitative relationships between several alternatives based on paired comparisons), and Probabilistic Thinking (ability to distinguish correctly the relative values of percentage probabilities). The abilities measured by the TRAT were derived from discussions in the literature on essential reasoning abilities.

The vignette abilities are scored by presenting the vignette to the patient, asking him or her if he or she needs further information, and asking him or her to choose one of the alternatives and give him or her reasons for doing so. The patient is then asked for further reasons, as well as for his or her least preferred choice and his or her reasons for his or her preferred choice. Scoring occurs by seeing how many of the kinds of cognitive operations identified earlier occur. For instance, did the patient compare risks and benefits of the alternatives with each other? The three further abilities (weighting consequences, transitive thinking, and probabilistic thinking) are scored by presenting the patient with a series of questions that tap into those abilities. For instance, to test Probabilistic Thinking the patient is told that some event has a 90% probability of occurring and is then asked if he or she thinks it likely to occur.

Finally, the TRAT has a question that measures the patient's ability to Express a Choice. A full score is received if the patient unambiguously chooses an option, and partial credit is received if the patient initially chooses two or no alternatives, but then chooses one alternative during a "repeat" inquiry.

Early indications are that two of the cognitive operations—Weighting Consequences and Seeking Information—are frequent outliers, and when factor analyses are performed with these subscales removed, they produce two very consistent factors; Consequential, Comparative, and Complex Thinking on the one hand, Transitive and Probabilistic Thinking together with Generating Consequences on the other. See THOMAS GRISSE &

ability to express a choice. Appelbaum and Grisso have designed these instruments to comport with standards of legal competency found in case law and statutes<sup>9</sup> and are careful to distinguish between capacity and competency. "Capacity" refers to abilities relevant to performing a task, while "competency" is a legal judgment that one has sufficient abilities to perform the task. Appelbaum and Grisso have designed their instruments to measure *capacities*.<sup>10</sup> A subject is "impaired" when he or she scores two standard deviations below the mean of those studied.<sup>11</sup>

The MacArthur researchers have recently designed a treatment capacity instrument to be used for actual evaluations rather than for research purposes (the MacArthur Competence Assessment Tool-Treatment, or MacCAT-T).<sup>12</sup> The MacCAT-T incorporates many of the questions found in the research instruments, yet is more efficient to administer and is tailored to the individual's particular situation. The investigators are careful to say that MacCAT-T scores do not determine competency.<sup>13</sup> Clinical judgment is required to make a definitive finding. The authors suggest that the MCAT-T be used in conjunction with a clinical evaluation that takes into account such things as contextual variables.

The results of the MacArthur research are intriguing. The most important is that a significant proportion of patients and nonpatients in all categories scored in the non-impaired range, although the schizophrenic patients did the least well. "Impaired" was defined as two standard deviations below the mean for the aggregate of everyone studied, patients and nonpatients alike. Given this definition,

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PAUL S. APPELBAUM, *MANUAL FOR THINKING RATIONALLY ABOUT TREATMENT* (1993) (unpublished manual available from authors).

9. See, e.g., *Constructing Competence*, *supra* note 5, at 363; *Hospitalized*, *supra* note 5, at 121; *MacArthur I*, *supra* note 5, at 108.

10. See, e.g., *ASSESSING COMPETENCE*, *supra* note 1, at 11.

11. See, e.g., *Constructing Competence*, *supra* note 5, at 373. This paper uses the terms "competency," "capacity," and "impaired" in the same way as do Berg, Appelbaum, and Grisso.

12. THOMAS GRISSO & PAUL S. APPELBAUM *MACARTHUR COMPETENCE TOOL-TREATMENT (MCCAT-T)* (1995) (unpublished manual available from authors). The MacCAT-T is a streamlined version of the MacArthur research instruments which aggregates all three research instruments (the UTD, POD, and TRAT). The evaluator is required to personalize the questions to the patient's particular situation. There is a greater effort than in the research instruments to try to determine the bases for the patient's answers, counting as impaired only answers based on considerations that appear grossly to distort reality. The researchers do not offer standardized means of determining what constitutes impairment. Rather, according to the MCAT-T the evaluator uses clinical judgment in determining which responses are impaired.

13. See, e.g., *id.*

approximately 25% of the schizophrenic patients scored in the impaired range on each of the three principal instruments, and approximately 50% scored as impaired when the scores on the different instruments were aggregated. (This means, of course, that 50% of the schizophrenic patients scored in the *nonimpaired* range when the scores were aggregated.)<sup>14</sup>

The second important finding of the study was that the three different instruments seemed to be picking out different patients. While scores on the UTD and the TRAT correlated well, scores on the POD did not correlate with scores on either the UTD or TRAT. The researchers conclude that because the research instruments pick out different groups of people as impaired, all should be incorporated in the MacCAT-T.

In terms of setting an actual standard for competency, the researchers consider two alternatives. The first is to use a fixed level of performance as a basis for a finding of competency—such as understanding, appreciating, and reasoning about 75% of the information provided. The second way of setting a standard is to vary the level of ability required based upon the net balance of expected benefits and risks of the patient's choice compared to the alternatives (i.e., more capacity is required for decisions when the risks are greater). The researchers suggest that they prefer the latter.<sup>15</sup>

### III. CHALLENGES TO THE MACARTHUR RESEARCH

The MacArthur instruments are based upon normative choices. A challenge to the MacArthur studies is to explain and justify these choices in a more detailed manner than has been done to date. Consider the

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14. The researchers noted that their study likely understated the rate of impairment, because the most disturbed patients were not deemed suitable for participation. Yet, this point is not entirely clear. The study looked only at recently hospitalized patients who were likely to be in the throes of the most acute phase of their illness. Later in their hospital stay their capacities may have improved. And a study evaluating schizophrenics in different settings, such as day hospitals, community mental health centers, and group homes, might well have found a higher percentage of schizophrenic patients scoring in the nonimpaired range. These patients, of course, also have to make treatment decisions. Insofar as schizophrenia is a chronic illness, studying schizophrenics' decision making abilities should include schizophrenic patients in a variety of settings, across a variety of times. In short, many patients—even those with the most severe psychiatric disorder—may be capable of making their own decisions.

15. See *infra* note 16.

following three areas that merit further normative discussions. First, the MacArthur researchers pick out certain capacities for their instruments to measure and label specific levels of these capacities “impaired.” Clearly, the researchers have deemed the chosen capacities relevant to competency and have determined that a certain level of the capacities—or their absence—is significant and should be considered in assessing competency. Next, the MacArthur researchers suggest that we should adopt a variable competency standard so that choices with a higher potential cost would require a higher level of competency.<sup>16</sup> Finally, the MacArthur researchers point out that the three main research instruments seem to be picking out different populations of patients, so that a treatment capacity instrument (the MacCAT-T) should aggregate the three measures. This judgment presupposes that all the skills measured by the three instruments are important to competency—a claim that merits further attention.<sup>17</sup>

Below we examine the MacArthur instruments in more detail. We first identify the abilities identified as essential to competency and then examine the extent to which the specific instruments protect all the values implicated in defining competency.

#### IV. EVALUATING SPECIFIC RESEARCH INSTRUMENTS

The MacArthur research instruments are designed to measure capacities relevant to the assessment of competency. The capacities measured by the instruments are: 1) pure comprehension of relevant information (the UTD);<sup>18</sup> the ability to assess evidence and form appropriate beliefs about that information (the POD);<sup>19</sup> the ability to

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16. See, e.g., *Constructing Competence*, *supra* note 5, at 385-87; ASSESSING COMPETENCE, *supra* note 1, at 127-48.

17. See, e.g., *Constructing Competence*, *supra* note 5, at 380-81. The authors suggest that there are *empirical* grounds to aggregate the standards because they pick out different groups. Aggregating the standards also raise a *normative* consideration, however, given that the standards pick out different groups. The normative consideration speaks to whether we think the capacities judged are important to competency.

18. By “pure comprehension” we mean grasping the meaning of what is said without necessarily believing what one has grasped. See Elyn R. Saks, *Competency to Refuse Treatment*, 69 N.C. L. REV. 945, 952-56 (1991).

19. The MacArthur’s UTD and POD incorporate more than merely the distinction between pure understanding and formation of beliefs. This distinction, however, between pure understanding and formation of beliefs, is an important aspect of the distinction drawn between what the UTD and POD measure. Elyn R. Saks & M. Litt, *Competency to Decide on Treatment and Research: The MacArthur Capacity Instruments*, in 2 NAT’L BIOETHICS ADVISORY COMM’N, RESEARCH INVOLVING PERSONS

reason with that information (the TRAT); and the ability to evidence a choice (subset of the TRAT). All of these abilities can be normatively justified as necessary for competent decision making.

Pure comprehension or understanding of relevant information is essential to competence. Imagine being asked to make an important decision, the implications of which are described in a foreign language. One is simply not in a position to decide. Pure understanding, then, is a clear prerequisite for competency.<sup>20</sup>

Pure understanding, while necessary, is not sufficient. The ability to assess evidence and form appropriate beliefs is also necessary. MacArthur's inclusion of this ability in its capacity instruments makes eminent sense. Because making a decision in one's best interests requires assessing how those interests are likely to be affected, the patient must be able to form adequate beliefs in order to be a competent decision maker.<sup>21</sup>

In addition to pure understanding and the ability to assess evidence and form appropriate beliefs, one also must be able to reason with some degree of intactness. Reasoning allows one to put together the relevant information one has purely understood and, having assessed, has formed beliefs about. Consider the following. A person desires *x* and wants to obtain *x*. She believes that *y* is the way to get *x* and knows that *not*

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20. Consider as well the following thought experiment. John, a captive, is forced, on pain of death, to decide between two contraptions. One of the contraptions will torture him and the other will grant his every wish. John cannot tell from looking at the contraptions what they will do, and he cannot understand his captors' explanation of them because they speak a foreign language that he does not understand. It seems plausible to say that John is incompetent to decide between the two contraptions—with one reservation. We may want to reserve the term "incompetent" for people who are not simply ignorant. Although well-known philosophers have justified paternalism in the face of ignorance (recall, e.g., John Stuart Mill's example of stopping a person from crossing an unsafe bridge in JOHN STUART MILL, *ON LIBERTY* 97-98 (Alburey Castell ed. 1947)), the law may prefer to reserve the term "incompetent" for those who lack abilities, perhaps as a function of their mental illness, rather than those who simply lack knowledge. Whatever we decide in the real world, surely most people would want, in our example above, to be disabled from deciding for themselves, and to have benign and knowledgeable others decide for them.

21. Decisions are based on desires and beliefs: One desires *x*, and believes that *y* is the way to get *x*, and thus one decides to do *y*. A deficiency in one's beliefs may therefore severely affect one's decision making capacity. One forms beliefs as a result of assessments of the evidence, so that the skill tapped here is the ability to assess evidence. This skill is clearly needed in some degree or another for competency.

doing y will guarantee *not* getting x. If she then concludes *not* to do y on the basis of deficient reasoning, her choice not to do y is not a competent choice. The MacArthur instruments rightly contain a measure of reasoning.

Finally, should making known (i.e., conveying to another) one's choice be considered a necessary skill for making a competent choice? It could reasonably be argued that making a choice known is not necessary to make a competent choice.<sup>22</sup> Nevertheless, *assessing* competency requires the communication of a choice that can then be assessed. Thus, the subtest in the MacArthur instruments measuring the ability to communicate a choice is justified.

The MacArthur instruments identify and assess abilities necessary and helpful in making decisions: understanding relevant information; assessing the evidence and forming appropriate beliefs about it; reasoning about the evidence with a degree of intactness; and communicating a choice. As such, the MacArthur Instruments are clearly sensitive to ensuring that vulnerable patients have the skills required to make important choices. In a word, the instruments safeguard the value of paternalism. How do the instruments factor in the values of autonomy and nondiscrimination?

#### A. *The UTD and TRAT*

The UTD is an impressive instrument. It spells out items of information that patients ought to understand, explains the information with a simple vocabulary, and tests understanding of the information in several different ways in order to allow patients full scope to demonstrate what they have learned. We would like to raise the question of whether the manner in which the UTD assesses pure understanding requires too high a price in the way of autonomy.

Consider that the UTD does not give credit for information patients give about their disease over and above what is recited in the UTD. Thus, a patient receives no points if she mentions real symptoms that were not part of the disclosure. The UTD's treatment of extra-disclosure information makes sense up to a point. It is important to assess whether the patient is able to listen and understand what he or she has been told.

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22. Consider, for example, a man who is paralyzed and unable to communicate. He may very well decide after careful consideration that he would like some procedure done. Suppose that by any (other) measure we could formulate he would be deemed competent. Does his inability to say what he wants make him incompetent? Not necessarily, insofar as we distinguish between *making* and *communicating* a choice. Of course, one can only *assess* a choice if that choice has been communicated.

Absent this ability, a patient cannot assimilate (and eventually assess) information relevant to his or her decision. On the other hand, respect for unconventionality—and so autonomy—might counsel allowing the patient completely to diverge from what has just been read, provided the patient recites *true* information about the relevant illness. Patients may get just as good information—or better information for their situation—from other sources. Perhaps they should be entitled to choose what information is important to them about their illness, as long as they understand *that* information. Indeed, given the patient's unique symptomatology, he or she may have better information relevant to his or her particular decision than that which the researcher has provided. What may be most salient about schizophrenia to the patient, for instance, may not be the voices mentioned in the disclosure, but the disorganization of his or her thinking process. That is what the patient recites as a symptom of schizophrenia. By slight alterations in the UTD, we might be able both to protect the vulnerable and to further promote their autonomy.

The TRAT does an impressive job in identifying and testing reasoning abilities necessary for competency. Just as with the UTD, however, a question can be raised concerning whether the TRAT requires too high a price in terms of protecting other values. The TRAT runs this risk in two ways: First, it may sometimes require abilities that do not really add to the individual patient's decision making process, and second, it may underestimate how often the cognitive processes deemed essential for competency are actually occurring.

Assessing the ability to reason is essential to assessing competency. Yet, how much reasoning ability should be required? It is unclear that pure or pristine reasoning plays an essential role in *all* effective decision making. Intuitive and idiosyncratic processes may actually improve decision making in certain instances (consider cases in which people dream of solutions to difficult mathematical problems, or police officers who solve a case on a "hunch"). Perhaps more important, even generally effective decision makers who indisputably have the ability to form accurate beliefs misuse statistics, misunderstand probabilities, and accord undue weight to vivid examples. They may also be profoundly affected by irrational and unconscious factors. Unless we are willing to declare most people incompetent, declaring only the mentally ill who lack reasoning skills incompetent risks unjustifiably discriminating against individuals on the basis of mental illness.

While the TRAT does seem to require the presence of only basic

abilities (e.g., in testing the understanding of probabilities, it requires only the understanding of a grossly obvious inference), it must also attempt to justify giving better scores for showing *more* abilities. A particular decision, for instance, may involve only two alternatives. In such a case, the relevance, say, of transitive thinking or complex versus comparative thinking may not be pertinent. More important, a patient might not engage in many of these cognitive functions because, for her, one consideration is decisive. As an example, she may so disvalue a risk of one of the alternatives that thinking consequentially is all she needs to do to choose between two alternatives. Thus, the patient's autonomy may be undervalued.

Another challenge to the TRAT is its requirement that one *evidence* (indicate the presence of) all of these other functions—functions that may be occurring at an implicit level. For instance, a woman who says “I want x and not y because I am terribly frightened of the significant seizure risk carried by y—my father died in a car accident as a result of a seizure when I was three” will often have gauged that x does not carry such a seizure risk (or anything equally aversive to the patient). She may well have done so and may simply not *say the words* “and I have compared x to y and x does not have any such abhorrent consequences to me.” In this case, she would not receive full credit on the TRAT. Perhaps instead of simply asking for reasons, the patient, once having given a reason, should be asked *directly* if she compared y to x and, if so, what in the comparison led to her choice. By possibly overlooking the patient's acceptable reasons for her choice, the TRAT may unnecessarily tread upon her autonomy.

## B. *The POD*

The POD taps the ability to assess evidence. As a consequence, it examines the quality of the patient's beliefs. Deciding what beliefs a patient must have to be deemed competent is a precarious endeavor indeed.

Accurate beliefs about the world are essential to competency, because decisions take effect in the world. Yet consider the following points. First, more often than we like to think, whether a belief is true is an open question. Very few beliefs are indisputable. As a consequence, requiring particular beliefs may not further our interest in protecting the vulnerable; if the belief we require is wrong, the patient is in no better position to decide. Freedom includes freedom to decide what is *true* no less than what is *good*. If we require particular beliefs, we prevent the patient from pursuing the truth according to his or her own lights. While

limits should be placed on what a patient can believe, too stringent limits severely curtail patients' freedom to be unconventional in their pursuit of truth. Moreover, many people have distorted beliefs that form the bases for their decisions. We risk discriminating against the mentally ill if we hold schizophrenics not competent on the basis of beliefs held by other, presumptively competent decision makers. Thus, too strictly assessing beliefs may infringe upon autonomy and nondiscrimination without offering clear protection to the vulnerable. How does the POD balance these three values?

The POD appears to require that patients believe what their doctors believe about their illness and treatment. A lower score is given on the POD for a patient who denies that he or she is ill, disagrees with the diagnosis given by his or her treater, or is more pessimistic about his or her prognosis than the treater. A subset of the POD, the NOD (Non-Acknowledgment of Disorder) measures appreciation of one's illness. The patient receives a full score if he or she accepts the diagnosis the doctor has provided, judges the illness as severe as a particular measure of symptom severity does, and accepts the symptoms reported in the chart. A second subset of the POD, the NOT (Non-Acknowledgment of Treatment Potential), measures acknowledgment of treatment potential. The NOT requires one to accept a good prognosis when treatment and medication exist for the condition, and a worse prognosis without treatment.<sup>23</sup>

Two challenges can be raised to the NOD. First, a doctor may be wrong about a patient's diagnosis. The reliability and validity of psychiatric diagnoses are often in doubt. Doctors often disagree about diagnoses, and sometimes disagree about the category of illness (e.g. psychotic disorder vs. mood disorder vs. personality disorder) and about whether a patient even has a significant illness. Put another way, the NOD is limited by the reliability and validity of psychiatric diagnosis. While the patient may be quite willing to believe an earlier doctor's diagnosis or even that he or she is seriously ill, the patient is counted as impaired by the NOD if he or she disagrees with this particular diagnosis.<sup>24</sup>

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23. If the patient has reasonable grounds to disagree with the doctor's judgment, a hypothesis nullifying his or her premise is presented, and he or she is again asked his or her beliefs. ("Imagine that a doctor tells you there is a medication that has been shown in research to help 90% of people with your problem, *even people who had not gotten better with any other medication.*").

24. The patient is told what diagnosis he or she has been given and then is asked

Second, the NOD asks whether the patient rates his or her symptoms as severe as the Brief Psychiatric Rating Scale (BPRS) does. A deviation from the BPRS counts against the patient. Yet, a response that diverges from the BPRS is not necessarily a profound distortion of reality. Moreover, the NOD is limited to the extent that the severity ratings of the BPRS are not highly reliable or valid.<sup>25</sup>

A challenge to the NOT is that doctors may simply be wrong about one's *particular* likelihood of benefiting from treatment and deteriorating without treatment. For instance, some patients may become demoralized and depressed at the need to take medication. Some of these patients may give up, stop trying to get better, just as some patients may regress in hospitals and never want to leave. It may be clear how patients on average do with and without a particular treatment—but averages don't speak to this particular patient, who may be *right* that he will be in the 10% that do not respond to a treatment.<sup>26</sup> Because no one can predict the future with complete confidence, it may be problematic to require patients to form beliefs about a particular outcome they will experience in the future. Asking patients to understand what happens generally makes sense; asking them to believe that the general rule will apply to them is a more complicated affair.<sup>27</sup>

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whether he or she agrees with this diagnosis. If the patient strongly or probably disagrees with the diagnosis, he or she receives a “zero” (as opposed to a “one” or “two”) on that item. The POD asks not only whether your doctor thinks you have this illness, but whether you think you have this illness as well. Because there are six parts of the POD (three for denial of illness and three for disagreement about prognosis with and without treatment), denial of illness alone would probably not render one incompetent, although it might render one “impaired.”

25. The third measure of the NOD seems less of a challenge to the value of autonomy. It asks whether patients acknowledge the presence of symptoms mentioned in their chart. Many of these symptoms will be grossly demonstrable. If a patient denies that he or she has just been frenetically pacing, or hasn't slept in days, he or she is severely distorting reality. Some symptoms, on the other hand, involve more interpretation. Is the patient agitated? Maybe not for him or her. Still other symptoms essentially duplicate the illness question, such as whether the patient is experiencing hallucinations or delusions (as opposed to asking whether the patient is seeing or hearing things that are not really there, or believing things that others don't believe). Alternatives should be considered to framing the question in terms of whether the patient is experiencing “delusions” or “hallucinations.”

26. In the MacCAT-T, the MacArthur researchers allow a patient to get a full score if he or she says he or she expects to be in the bottom 10% because previous treatments have failed for him or her. But the patient may also have his or her own reasons—perhaps even superstitious ones—for thinking that treatment will fail now and he or she will be in the bottom 10%. Once again, he or she may be right—many people are simply pessimistic about treatment. Or, the patient may be reacting defensively to guard against the possibility of future disappointments, a recognized and sometimes effective strategy.

27. To look at this in another way, the NOT may actually measure optimism and

How might these challenges to the POD be met? Beliefs one could require for competency cover a range. At the far end is the view incorporated in the POD, which provides full credit when the patient believes what the doctor believes. At the other end of the range is the view that patients can believe virtually anything, except, perhaps, things impossible by their very nature. Within these extremes other standards are possible. Perhaps competency should be premised on believing what *most* doctors would believe about an illness and treatment. Or perhaps competency should be premised on believing what most *people* would believe. Or upon what most *reasonable* people believe. Or perhaps we should dispense with norms altogether and attempt to characterize a competency standard in a way that does not refer to majorities.

We suggest a standard for competency that finds a middle ground between an “impossible belief” standard, on the one hand, and a “believe what your doctor believes” standard, on the other. As we see it, a standard of competency should not turn on whatever a doctor believes about an illness and its symptoms, treatment, and prognosis. Conversely, beliefs that grossly distort reality, that are based on little or no evidence, or that are indisputably false or patently delusional should, in our opinion, render one incompetent.

The standard we propose is a “patently false delusional belief” standard. Patently false beliefs are beliefs that are grossly improbable, for any one of several reasons. First, patently false delusional beliefs may violate the laws of nature. An example would be that *thoughts can kill*. Second, a patently false delusional belief may also be a belief that does not violate the laws of nature, but one that is practically impossible; that is, a belief so improbable that we feel confident in saying it is false without additional evidence. An example would be that one is able to calculate as fast as a supercomputer. Finally, a patently false delusional belief may be a belief that represents a gross distortion of obvious facts; that is, a belief that flies in the face of empirical happenings obvious to everyone. An example would be that a large spaceship lies in the middle of New York’s Central Park. Patently false delusional beliefs are beliefs that are grossly improbable in one of these three ways. Religious and cultural beliefs are exempted from the definition of patently false beliefs, as are beliefs commonly held in a society or culture even if they appear odd or idiosyncratic to people outside the society or culture.

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pessimism. Many people are unduly optimistic or pessimistic about many things. The NOT may require patients to manifest a trait—optimism—that many people may lack.

We would like to propose further normative discussion about the POD in another regard by suggesting that mere denial of mental illness should not necessarily count against one in a competency assessment.<sup>28</sup> This claim—that denial of a mental illness does not always count against competency—can be made without denying either the reality of mental illness or the severe suffering it causes. One can also hold this view and continue to subscribe to the medical model.<sup>29</sup> Consider the following seven reasons a patient might deny his or her illness.

First, a person denying he or she is mentally ill may simply not be willing to admit to something that is stigmatizing and carries negative consequences in our society. Attempting to avoid the negative consequences of a diagnosis may be a rational strategy as a way to move on in one's life.

Second, a person denying his or her illness may be acting on the basis of an understandable defense. Denial of difficult things is quite common. Denial can be a way to protect one from the narcissistic injury of having a mental illness.

Third, denial can be adaptive. Evidence suggests that people with serious physical illnesses live longer if they deny the seriousness of their illness.<sup>30</sup> A person denying he or she is mentally ill might draw on resources he or she would be too discouraged to use if the person admitted the illness.

Fourth, diagnoses of mental illness are generally less certain than many diagnoses of physical illnesses. Unlike physical illnesses, where there often are definitive findings that unequivocally establish the diagnosis, there are no physical tests for any nonorganic mental illness. This point is epistemological, not ontological. To say that we cannot definitively prove someone has soft tissue damage is not to deny that there is such an illness as soft tissue damage or that soft tissue damage can cause considerable pain and disability. The two issues are different. We can hold to the medical model, retain our belief in the reality of mental illness, and still claim that denial of mental illness ought not automatically to count against competency.

Fifth, many members of society are skeptical about mental illness—or at least about whether particular behavior patterns or symptom

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28. See Saks, *supra* note 18, at 988-92 (discussing denial of mental illness). Since that publication, Saks' views on denial have changed somewhat.

29. In this context, the "medical model" is the model according to which mental illnesses are real disease entities, as much so as any physical illnesses, and therefore respond to treatments of various kinds. According to the medical model, mental illness is not simply "problems in living."

30. See Saks, *supra* note 18, at 990 (mentioning sources supporting this claim).

constellations amount to a mental illness.<sup>31</sup> Beliefs that mental illness is a failure of will, consists of problems in living, or is motivated by a desire to be cared for are not uncommon. While some such beliefs amount to frank prejudice, or are at the very least based on ignorance, the point is that if these beliefs are not uncommon, then a particular patient's similar belief does not represent a gross departure from ordinary ways of thinking. To hold that such a belief should render one incompetent is to risk discriminating against the mentally ill.

Sixth, it *does* represent a patent distortion of reality to deny that one is suffering from grossly demonstrable symptoms. But the patient who can admit that he or she is agitated, pacing, scared—whatever his or her symptoms happen to be—has reason to accept treatment that doctors say will help those symptoms abate. It is not clear that we need to make the patient admit to having a mental illness. It risks forcing a humiliation on the person to do so.<sup>32</sup>

Finally, many populations of patients are notoriously noncompliant with treatment recommendations.<sup>33</sup> Such noncompliance could be

31. Beliefs such as these about mental illness seem much more common than beliefs about physical illness. Even certain mental health professionals have similar views about mental illness; Szasz, for instance, denies that any nonorganic mental illness is real. See, e.g., THOMAS S. SZASZ, *THE MYTH OF MENTAL ILLNESS: FOUNDATIONS OF A THEORY OF PERSONAL CONDUCT* (2nd ed. rev. 1974).

32. Perhaps, however, we should require more. For example, we should require that patients need to accept not only that they are pacing, but that they have *some* condition, even if it is not the condition their doctors say they have. Or perhaps we should require the patient to admit that he or she has some condition that *looks like* schizophrenia that most doctors would so diagnose, and that is thought antecedently to be as likely to benefit from treatment as any other similar presentation. These claims are fairly indisputable in many cases. We don't *need* a physiological test to establish them. Thus, while a patient may not trust what the individual doctor is telling him or her about his or her diagnosis, the patient can and should accept the fact he or she has symptoms commonly used by psychiatrists to identify mental disorders (e.g., the patient simply denies their significance in terms of whether he or she "has" the illness.). See AMERICAN PSYCHIATRIC ASS'N, *DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS (DSM-IV)* (4th ed. 1994). It seems a close call whether we require these additional beliefs or whether simply admitting to one's symptoms and one's doctor's belief in potential benefit of treatment is enough to establish competency. An intermediate position would be to require patients to admit, simply, that "something's wrong."

33. See, e.g., Joyce A. Cramer et al., *How Often Is Medication Taken as Prescribed? A Novel Assessment Technique*, 261 JAMA 3273 (1989); Richard L. Ruffalo et al., *Patient Compliance*, 31 AM. FAM. PHYSICIAN 93 (1985); Barbara J. Stephenson et al., *Is This Patient Taking the Treatment as Prescribed?*, 269 JAMA 2779 (1993).

interpreted as an unconscious denial of illness. To the extent this interpretation is plausible, we risk discriminating against the mentally ill by penalizing *their* denial.

Given these reasons for denial, it seems appropriate to probe when a patient denies he or she is mentally ill in order to see if the patient's reasoning is understandable.<sup>34</sup> Perhaps the patient is not speaking honestly. For example, perhaps a man is narcissistically wounded but, in his heart of hearts, knows the truth. Perhaps he thinks of his behaviors as his choice. Perhaps he holds widely held views about mental illness that lead him to think he is not really ill, beliefs that are reinforced by his family or friends. In short, one should explore whether a given case of denial amounts to a patent distortion of reality (e.g., "aliens are causing me to suffer to save the world"). On this view, if a belief is not impossible, then one must consider how plausible it is, and whether it is an understandable or common belief, to determine whether the belief patently distorts reality.

One final cautionary note about denial: Allowing denial to be a basis for a finding of incompetency—and thus forced treatment—is fraught with danger. Not only would finding incompetency on the basis of denial permit us to force treatment on an obsessive-compulsive person who denies that he or she is ill—and who among us is free of maladaptive personality traits?—but it would also allow us to characterize political dissidents as ill, and then to use their understandable denial that they are ill as a basis for their involuntary treatment.

In sum, more substantive points for future normative discussion can be raised about the POD than about the UTD or TRAT. This discussion might fruitfully explore what kind of beliefs are sufficient for competency and what kind of beliefs are not. As examples, a standard might look to whether the patient denies what his or her doctor says, what most doctors say, what most reasonable people would say, what is patently true, what must be true, and what cannot be true. Future

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34. A failure to probe may result in *underestimating* the presence of incompetency by focusing too exclusively on disavowal of what one's doctor believes and not enough on the degree of distortion which the belief represents. Take the patient who admits he or she has the diagnosis the doctor gives and agrees with the doctor's prognosis with and without treatment. This person would receive a full score on the POD. But suppose he or she also believes that he or she has the diagnosis the doctor gives because aliens are manipulating his or her neurotransmitters from afar, and that taking the medication will enrage the aliens and cause them to destroy the earth—even though he or she thinks it will cure his illness. Again, this person would receive a full score on the POD. But is he or she really competent to refuse treatment? Do we not want to look for patently false beliefs and not just disagreement (or agreement) with what one's doctor says?

scholars would establish which level of each belief to require. We suggest a patently false belief standard as a likely candidate to separate those competent to make decisions from those who are not. Whichever standard is chosen, serious consideration will need to be given to the role of denial in assessing competency.

The MacArthur research instruments identify the abilities both helpful and necessary to make decisions and thus serve the value of protecting the vulnerable. Their emphasis on protecting the vulnerable, however, necessarily comes at the price of placing less emphasis on other values implicated in setting standards for competency: the value of protecting autonomy, even when autonomous choices are unconventional, and the value of safeguarding against discrimination. A challenge to the MacArthur researchers is to justify striking this balance in the manner they have. For example, an objection could be raised to their way of balancing values by claiming that freedom of choice includes both the freedom to choose and the freedom to choose *how* to choose—the patient’s decision making *process* implicates the same normative issues as does the patient’s *choice*. And we should not require more of mentally ill patients in this regard than we do of any other individuals.

### C. *The MacCAT-T*

The MacCAT-T is a streamlined version of the three research instruments. It is designed to aid in assessing competency in an actual clinical setting. The MacCAT-T is the best instrument currently available of its kind. We raise three points to consider about the MacCAT-T’s application in direct clinical care.

First, the “appreciation” component of the MacCAT-T acknowledges the difference between nonagreement with one’s doctor that is nondelusional (i.e., has some reasonable explanation) and nonagreement that is “based on a delusional premise or some other belief that seriously distorts reality and does not have a reasonable basis in the patient’s cultural or religious background.”<sup>35</sup> The range of “reasonable explanations” given, however, may be overly narrow. Only culturally or religiously sanctioned beliefs are permitted to ground “reasonable” disagreements. The MacCAT-T scores as “zero” a patient’s belief that

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35. THOMAS GRISSO & PAUL S. APPELBAUM, MACARTHUR COMPETENCE ASSESSMENT TOOL—TREATMENT (MACCAT-T) 12 (1995) (unpublished manual available from authors).

his symptoms are related to circumstances other than a psychiatric disorder, such as stress or overwork. Given widespread beliefs in our society about psychological distress, a patient could be holding non-*patently* false ideas were he to attribute the cause of his symptoms to reasons outside what the MacCAT-T views as permissible.

A second point to consider about the MacCAT-T, insofar as it will be the instrument used in an actual clinical setting, is the suggestion<sup>36</sup> that competency exists on a sliding scale, and that the individual evaluator will play a central role in setting the standard when the patient is faced with a choice about treatment. If the patient chooses an alternative that goes against conventional wisdom—say, to reject a treatment with proven efficacy for a serious illness—the evaluator could require a higher level of abilities of the patient. Put another way, according to the MacCAT-T the standard for competency will vary as if on a sliding scale: If patients are about to choose something that will not help them and may harm them, the MacCAT-T deems it especially important to assess whether they know what they are getting themselves into. The evaluator conducting the assessment would judge whether the level of ability would need to be raised given the particular choice at issue and would do so according to how he or she deemed it appropriate.

A challenge to this proposal arises. Doing so seems only a distant cousin to declaring people who make good choices competent and people who make bad choices incompetent. One might respond to the challenge by pointing out that in assessing competency, autonomy is balanced against well-being, so that striking the balance differently when well-being is likely to be affected more seriously makes perfect sense. But there is a difference between saying that one must have certain abilities as a general matter in order to take responsibility for one's own choices, without scrutiny of particular choices, and saying that one must have *more* abilities when society judges that a *particular* choice is bad, or at least not as good as other choices. In addition, this manner of assessing competency allows the evaluator to determine that a choice is problematic based upon his or her own values, rather than on a set of values identified through normative discussion.<sup>37</sup> Perhaps at the end of the day competency doctrine should set the balance once, in order to avoid second-guessing patients' decisions. It could convincingly be argued, for example, that giving a third party the power to decide what is

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36. See *supra* note 16.

37. Individual evaluators will make decisions regarding which direction, and how far, the scale should "slide." These decisions will inevitably be based upon normative considerations. It is not clear that such considerations should be left to individual mental health professionals, rather than made through normative deliberation.

a good and a not-so-good choice defeats the very notion of competency—that the concept of competency leaves the choice up to the *patient*. One possibility would be to increase the level that we require of patients only in the most exigent circumstances: when a choice exposes the patient to a serious risk of very substantial, perhaps irreversible harm. This policy would minimize the occurrence of individual evaluators making normative judgments about a patient's choice of treatment.

Third, there is a real danger that an investigator faced with a requirement to use the MacArthur instruments may simply adopt its definition of "impairment" as the cutoff point for incompetence, or decide that the line the MacArthur researchers say indicates clear competence should also be the line below which a person is deemed incompetent. That is to say, in practical terms future competency administrators may mistake the nature of certain of the instruments so that "impairment" simply translates into "incompetency," or that the standard given for "clearly competent" on the MacCAT-T is used to divide the competent from the incompetent. It will be important to see whether such mistakes are being made.

#### V. IMPORTING THE MACARTHUR INSTRUMENTS INTO THE RESEARCH CONTEXT

The MacArthur instruments were designed for measuring capacities relevant to competency to consent to treatment. Two questions arise at the prospect of importing the instruments into the research arena: First, what, if any, normative considerations unique to participation in research will need to be addressed?<sup>38</sup> Second, to the extent that the same abilities are relevant in both the treatment and research contexts, will the manner of assessing these abilities need to be adapted to the research setting?

In regard to the first question, research implicates normative issues not raised in the treatment context. As an example, we must factor into our

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38. The MacArthur researchers have a book chapter in press that discusses adapting their instruments to the research context. See *Subjects' Capacity*, *supra* note 5. The authors state that the instruments must be adapted to the research context (e.g., the UTD must disclose information appropriate to participation in research), and they point to the added value of increasing scientific knowledge. The authors also suggest adopting a sliding scale approach, so that each evaluator is free to draw the line between autonomy and paternalism as he or she sees best.

balance of autonomy, paternalism, and nondiscrimination a new value: that of advancing science. A question raised by the addition of this new value is whether competence in the research context requires greater capacities. Reasons argue both for and against requiring greater capacities.

In terms of reasons for raising the standard for capacity, consider that the patient/subject will be consenting to participate in activities for the benefit of others, possibly to his or her detriment.<sup>39</sup> We may therefore want patient/subjects to play a larger role in evaluating a decision to participate in research, so that correspondingly higher capacities are required. In addition, we may think that as a risk-of-error matter evaluators are likelier to have an interest in finding competency so that their patients will be able to consent to research that will help the researchers. To offset this likely bias, the standard for competency should likewise be raised.<sup>40</sup> Finally, given the intense transference people sometimes bring to doctor/patient interactions, the patient/subject may not be in a good position to protect himself or herself—that is, to make the best judgment for himself or herself in the absence of a doctor whose *sole* concern it is to assist in making a good judgment for the patient.<sup>41</sup> Reasons that speak against requiring a higher level of competency include a desire to participate in therapeutic research when nothing else seems to help. In addition, people can derive great utility from the thought of helping others and can feel terribly demeaned when their choice to do so is not respected.

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39. A variation on this position is that not a great deal is lost by not allowing patient/subjects the opportunity to participate in research. A second variation is that the decision to participate in research is of less benefit to the patient/subject than is the decision to consent to conventional treatment. While the reader will readily appreciate situations in which the second variation is not true, as a broad generality it seems sound.

40. The National Bioethics Advisory Commission recommends an independent professional to assess the subject's capacity to consent to research that involves more than a minimal risk. See *Recommendation 8*, 1 NAT'L BIOETHICS ADVISORY COMM'N, RESEARCH INVOLVING PERSONS WITH MENTAL DISORDERS THAT MAY AFFECT DECISIONMAKING CAPACITY (1998) (visited July 2, 1999) <<http://www.bioethics.gov/capacity/TOC.htm>>.

41. Patients may have many unconscious reasons to consent to research when a doctor asks them to do so. A positive transference—a desire to please the doctor—may be the most powerful, but the subject/patient may also experience a desire not to be the object of the doctor's animus; a belief that the doctor offers protection from all harm and that the doctor *must* have only the patient's interests at heart. In addition, patients may believe that they will not get other therapeutic treatment if they are unwilling to participate, will get the best treatment only if they participate, will be able to survive financially only if they are treated through a research protocol. Finally, the doctor may put some pressure on the patient to consent, and many people have a difficult time saying no.

The question of whether additional capacities are appropriate for competency to consent in the research context will require a thorough normative discussion. The fundamental condition of research, that the patient/subject serves the interests of both the patient and another,<sup>42</sup> speaks in favor of protecting the vulnerable. Allowing patient/subjects the choice to participate in research, and not requiring more of the mentally ill than other populations before consent is valid, speak in favor of autonomy and nondiscrimination. Discussion and debate are required to find the best balance of the values at play.

Second, the MacArthur instruments have been designed to aid in assessing competence to consent to treatment, and their manner of assessing capacities will therefore need to be adapted for the research context. The UTD, for example, will need to include the most important information patient/subjects need to understand about the research.<sup>43</sup> Most important, patient/subjects will need to understand that nontherapeutic research will not help them, and that research doctors have a primary interest in conducting research, not in providing care. The POD will need to be adapted in order to assess the patient's appreciation (belief formation) on these and other matters relevant to the research. Thus, the various instruments will need content that speaks to research.

## VI. CONCLUSION

The MacArthur instruments make an enormous contribution to the literature on competency. This article has raised and discussed areas where further discussion may prove fruitful. First, the normative underpinnings of the project merit further discussion. Second, the balance between autonomy, paternalism, and nondiscrimination merits further examination with an eye toward possible reassessment in certain, specific areas. Third, the role of denial merits reconsideration, especially the question of whether denying one's mental illness is in all cases relevant to the question of competency. Finally, a standard of belief in the appreciation instrument could be adopted. To the extent that the normative inquiry leads to a "patently false belief" standard, that

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42. In nontherapeutic research, the patient may have a strong interest in wanting to help others.

43. See *supra* note 6.

standard will need to be operationalized.<sup>44</sup> Notwithstanding these areas

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44. A 1996 symposium issue of *Psychology, Public Policy, and Law* that was devoted to the MacArthur Treatment Capacity research instruments contains a number of articles critiquing the POD. See Christopher Slobogin, "Appreciation" as a Measure of Competency: Some Thoughts About the MacArthur Group's Approach, 2 PSYCHOL. PUB. POL'Y & L. 18 (1996) (critiquing approach based on earlier writings of Elyn Saks); Susan Stefan, *Race, Competence Testing, and Disability Law: A Review of the MacArthur Competence Research*, 2 PSYCHOL. PUB. POL'Y & L. 31 (1996) (critiquing instrument on similar grounds); Trudi Kirk & Donald Bersoff, *How Many Procedural Safeguards Does It Take to Get a Psychiatrist to Leave the Lightbulb Unchanged? A Due Process Analysis of the MacArthur Treatment Competence Study*, 2 PSYCHOL. PUB. POL'Y & L. 45 (1996) (critiquing instrument).

The authors have several responses to this critique. First, they note that the critics all seem to want *some* measure of appreciation of illness and treatment to be included in a competency instrument, even if they object to the precise measure used. Second, they suggest that they may well not be all that far apart from their critics in the measure they want: The researchers acknowledge that mere nonacknowledgment of one's disorder, or of the realistic consequences of treatment, is not enough to constitute incapacity. The MacArthur researchers believe that, to speak to the question of capacity, the acknowledgment must be related to delusional thinking or other medical or psychological conditions that are responsible for a serious distortion of reality. They add that they accept the concept of a "patently false belief," provided it is not restricted to delusions but may also include nondelusional reasons for denying the existence of one's disorder, such as parietal lobe damage or intolerable anxiety related to recognition of the disorder. Third, they acknowledge that their instrument does not formulate a criterion for "patently false beliefs," and suggest that it was difficult for them to operationalize this concept; they invite others to try. Finally, the MacArthur researchers note that the MacCAT-T requires clinicians to make a judgment about patients' reasons for denial of their symptoms in order to rate their appreciation. The requirement represents an effort to include the "patently false belief" component in the capacity standard. The authors thought it possible to do so only by relying on clinical judgment, at the cost of sacrificing some psychometric reliability. Thomas Grisso & Paul S. Appelbaum, *The Values and Limits of the MacArthur Treatment Competence Study*, 2 PSYCHOL. PUB. POL'Y & L. 167 (1996).

The authors' first point is well-taken. A decision maker's beliefs are central to competency. The authors' second point, however, merits further discussion. The authors say they want to pick out only beliefs that seriously distort reality. While there may be a variety of reasons for serious distortions of reality, such as anxiety or dissociation (although if the distortions are serious, don't they necessarily *amount* to delusions?), it remains that denial of *mental* illness is often *not* a sufficient distortion of reality to justify a finding of incompetency.

The authors' third point, that (although they generally approve of the notion), they find the concept of a "patently false belief" difficult to operationalize, is a challenge that awaits future research. It will be important first to define a patently false belief as precisely as possible. The manner in which the MacArthur researchers discuss this concept indicates important conceptual differences in how a "patently false delusional belief" has been defined and discussed elsewhere.

Finally, the authors note that the MacCAT-T attempts to introduce the notion of a "patently false belief" by requiring examiners to assess the reasons for patients' denial.

of future work, the MacArthur instruments are an enormously impressive achievement and will no doubt be a focal point for the discussion of competency for many years to come.

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Given this approach, well-reasoned bases for disagreement with one's doctor would not count against one's competency, as they currently do according to the POD. While this approach seems correct and workable, the reasons that the researchers *would* allow to justify disavowals may be overly restrictive.

