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Illusory Consent: When an Incapacitated Patient Agrees to Treatment

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ABSTRACT: Medical treatment requires informed consent, which in turn requires decision making capacity. When a patient with questionable capacity does not resist treatment, these requirements are often neglected: treatment is administered with no assessment of capacity and no consideration of alternative decision making. A variety of ethical and legal forces contribute to this neglect. The practical effect is that patients are treated when, if they had capacity, they would refuse treatment. This subverts the dominant interest in health care decision making: patient autonomy.

After surveying current law and practice, this article addresses the following issues: (1) when to test patients for capacity; (2) how to test capacity; and (3) what to do when capacity is lacking. The guiding principle throughout is that treatment decisions should correspond as closely as possible to patients' true preferences. On the first question, existing data and new theory are marshaled in support of mandatory capacity assessment in various circumstances. Second, this article argues that standardized instruments rather than physician discretion should be used to assess capacity. Third, when capacity is lacking and the patient does not resist treatment, a familial surrogate should make the medical decision because family predict patient preferences better than doctors.

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Introduction

Hundreds of thousands of Americans each year sign pieces of paper "voluntarily" admitting themselves into psychiatric hospitals.[1] Many, perhaps most, do not understand the legal significance of the piece of paper, which drastically curtails individual freedom. In some states, signing the paper means that the patient can be held against his will for up to five days before the facility has to release him or attempt to justify continued detention.

Although the effect on personal liberty is generally not as severe, much the same thing routinely happens with respect to other health care decisions. Doctors often treat patients with dubious capacity who do not object to treatment without assessing capacity and without considering alternative decision making. Lack of capacity promises to be a growing issue as the population ages because dementia prevalence increases exponentially with age.[2]

Capacity is critical because the doctrine of informed consent requires that the patient have capacity to consent.[3] But this requirement is overwhelmed by forces pulling in the opposite direction. First, law presumes capacity. Second, the primary ethical goal of beneficence, improving patient well being, guides medical practice. If the patient is agreeing to do what the doctor believes in the patient's best interests, the doctor looks no further and simply presumes capacity.

The practice of treating without meaningful consent violates the fundamental principle of patient autonomy or self-determination. Assent without capacity is not an expression of autonomy,

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[1]Bruce J. Winick, *Competency to Voluntary Hospitalization: A Therapeutic Jurisprudence Analysis of* Zinermon v. Burch, 14 INT'L J. L. & PSYCHIATRY 169, 179 (1991).

[2]J.G. Wong et al., *Capacity to Make Health Care Decisions: Its Importance in Clinical Practice*, 29 PSYCHOLOGICAL MED. 437, 438 (1999).

[3]Wendy M. Margolis, *The Doctor Knows Best?: Patient Capacity For Health Care Decisionmaking*, 71 OR. L. REV. 909, 918-19 (1992).

it is at best an illusion of autonomy. The practical problem with accepting incompetent consent is that it systematically leads to treatment where patients, if they had capacity, would refuse it. Self-determination is and should be the dominant objective in medical decision making and it should be implemented by minimizing instances in which treatment deviates from what the patient, if competent, would want.

Some commentators believe that incompetent consent is not a problem. "If a patient consents to treatment, his or her competency is not important if a finding of incompetency would likely lead to treatment."[4] The words "likely," "if," and "consents" should ring alarms. As for likely, the issue of competency is important if treatment sometimes, even if less than half the time, would be refused by an alternative decision making scheme. The second "if" raises the question of who decides whether treatment is likely given an incompetency finding. Accepting incompetent patient assent at face value cedes control over the treatment decision to the doctor. Evidence shows that doctors are worse than relatives in predicting patient treatment preferences. The better and more direct way to find out whether an alternative decision maker would consent to treatment is to test capacity, then simply ask if appropriate. Finally, and most fundamentally, a patient cannot "consent" without capacity, and treatment without capable consent is medical battery.[5] As the reader will have noticed, "competence" is sometimes used here instead of "capacity." The terms are equivalent for purposes of this article. Both mean the ability to give informed consent to medical treatment. This article will generally use capacity rather than competence for several reasons: "incapacitated" is less

[4]Elyn R. Saks & Dilip V. Jeste, *Capacity to Consent to or Refuse Treatment and/or Research: Theoretical Considerations*, 24 BEHAV. SCI. L. 411, 423 (2006).

[5]*Franklin v. United States*, 992 F.2d 1492, 1497 (10th Cir. 1993). It is therefore misleading to speak about competency to *refuse* treatment, *see* Saks & Jeste, *supra* note 4, at 423: it is treatment, not the lack of treatment, that must be justified.

stigmatizing than "incompetent," capacity is more likely to be properly construed as task-specific, and capacity has more clinical connotations, which are this article's focus.

This article will examine three hypotheticals involving health care decision making. The issue in each will be how to make a medical decision when the patient does not refuse treatment but may lack decision making capacity. The article will first discuss how treatment decisions are actually being made, then examine how these decisions are supposed to be made under current law. For concreteness, the focus will be on Illinois law, but the implications will be general. Next, the article will propose and defend a new model of decision making. The issues addressed will be: when to test capacity, how to test capacity, and what to do when capacity is lacking. The final section before the conclusion will consider possible extensions of the model to instances in which no surrogate is available or the patient refuses treatment.

Hypotheticals:

> (1) The doctor of an elderly married woman with delirium concludes that the patient would benefit from a non-emergent blood transfusion. The patient assents[6] to the transfusion.
>
> (2) A widow with dementia is having evening delusions. Her clinic doctor would like to prescribe an anti-psychotic medication. The patient assents to treatment.
>
> (3) An unmarried bipolar man presents to a mental health care facility experiencing manic symptoms. The patient is willing to sign a voluntary admission form.

I. CURRENT PRACTICE

In all three hypotheticals, it is quite likely that the patient would receive treatment with no further examination of patient capacity and no exploration of alternative decision making. "Questions concerning patient competence tend to be raised only when patients decline to follow

[6]The word "assent" rather than "consent" is used here because the patient may lack capacity to give informed consent.

physicians' recommendations . . . ."[7] In one retrospective study of informed consent practices, "nearly all" patients in a hospital setting studied had "questionable decision-making capacity," but "only patients who refused treatment had their competence challenged."[8] In one epidemiologic study of older inpatients who developed delirium, researchers found no documented assessments of decision making capacity.[9] This despite a "relatively high baseline rate of functional impairment (76%) . . . and notable cognitive impairment (mean MMSE of 20.1)."[10]

In another study surveying specialists, 89% of respondent psychiatrists, psychologists, and geriatricians reported that the following misconception regarding capacity determinations was either "common" or "very common" among referring clinicians: "As long as a patient agrees with the practitioner's health care recommendations, the practitioner fails to consider that the patient may lack capacity for decisions."[11] Among 16 capacity pitfalls thought by respondents to be most important to address through education, this was the one that the highest percentage of respondents

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[7]Thomas Grisso & Paul S. Appelbaum, *The MacArthur Treatment Competence Study. III: Abilities of Patients to Consent to Psychiatric and Medical Treatment*, 19 L. & HUMAN BEHAV. 149, 171 (1995).

[8]Bennett S. Gurian, *Informed Consent for Neuroleptics with Elderly Patients in Two Settings*, 38 J. AM. GERIATRICS SOC'Y 37, 42 (1990); *see also* Michael G. Farnsworth, *Competency Evaluations in a General Hospital*, 31 PSYCHOSOMATICS 60, 61 (1990) ("patients who refused medical treatment were more commonly referred for evaluation of competence than were patients who accepted treatment").

[9]Katherine B. Auerswald, *The Informed Consent Process in Older Patients Who Developed Delirium: A Clinical Epidemiologic Study*, 103 AM. J. MED. 410, 410 (1997).

[10]*Id.* at 413. "MMSE" stands for Mini-Mental State Examination, which is a 30-point cognitive function screening tool. A score of 20 is at the low end of the mild dementia range. http://en.wikipedia.org/wiki/Mini-mental_state_examination.

[11]Linda Ganzini et al., *Pitfalls in Assessment of Decision-Making Capacity*, 44 PSYCHOSOMATICS 237, 239 tbl.1 (May-June 2003).

(52%) believed was "very common."[12]

Treatment without a capacity evaluation is most likely in Hypothetical (3), even though that is where the likelihood of incapacity and burdens of treatment are arguably greatest. As another commentator notes, "Because most mental health professionals favor voluntary admission, 'in practice the question of competence is usually ignored.'"[13] As will be demonstrated below, the law in Illinois and other states exacerbates this practice.[14]

II. CURRENT LAW

A. Hypothetical (1): Delirious Patient—Blood Transfusion

Administering medical treatment without informed consent from a patient with capacity (absent an emergency,[15] which this article assumes) is medical battery. Thus, the doctor should first determine whether the patient has the capacity to give informed consent. Because the common law presumes that all adults have capacity,[16] however, this may be an ethical rather than legal obligation.[17] Under the Illinois Health Care Surrogate Act (the "Act"), "'[d]ecisional capacity' means the ability to understand and appreciate the nature and consequences of a decision regarding medical

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[12]*Id.* at 239-40 tbl. 1.

[13]Karna Halverson, *Voluntary Admission and Treatment of Incompetent Persons with Mental Illness*, 32 WM. MITCHELL L. REV. 161, 168 (2005) (quoting THOMAS GUTHEIL & PAUL APPELBAUM, CLINICAL HANDBOOK OF PSYCHIATRY AND THE LAW 38 (3d ed. 2000)).

[14]Federal law, discussed below, discourages the practice, *Zinermon v. Burch*, 494 U.S. 113 (1990), but it is widely ignored, *e.g.*, *Wilson v. Formigoni*, 42 F.3d 1060, 1062-63 (7th Cir. 1994).

[15]405 ILCS 5/2-111.

[16]*E.g.*, *Lotman v. Security Mut. Life Ins. Co.*, 478 F.2d 868, 873 (3d Cir. 1973). *But cf. In re Estate of Allen*, 365 Ill. App. 3d 378, 389, 848 N.E.2d 202, 214 (2d Dist. 2006) (stating in dicta that presumption of capacity arising from statute, *see infra*, does not apply to claim for medical battery).

[17]AMA CODE OF MEDICAL ETHICS E-8.08 (2007) ("Informed consent is a basic policy in both ethics and law that physicians must honor . . . .").

treatment or forgoing life-sustaining treatment and the ability to reach and communicate an informed decision in the matter as determined by the attending physician."[18] Everyone is presumed to have capacity for purposes of the Act "in the absence of actual notice to the contrary."[19] Thus, that the doctor reasonably *should* know a patient lacks capacity does not override the presumption.[20] The attending physician must find incapacity "to a reasonable degree of medical certainty."[21] In the hypothetical this means that the doctor will accept the patient's assent to the transfusion unless the doctor is reasonably certain that the patient lacks capacity. Such a finding must be put in writing in the patient's medical record.[22]

If the doctor finds incapacity, she must next make reasonable inquiry into the existence of an

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[18]755 ILCS 40/10. This standard is generally consistent with the Uniform Health-Care Decisions Act and the leading summary of legal competence in the medical literature. *See* Unif. Health-Care Decisions Act § 1(3) (1994) ("'Capacity' means an individual's ability to understand the significant benefits, risks, and alternatives to proposed health care and to make and communicate a health-care decision."); Paul S. Appelbaum & Thomas Grisso, *Assessing Patients' Capacities to Consent to Treatment*, 319 NEW ENGLAND J. MED. 1635 (1988) (listing abilities to communicate choices, understand relevant information, appreciate the situation and consequences, and manipulate information rationally). The distinction between understanding and appreciation is not self-evident. Appreciation can be thought of as applied understanding: acknowledging the personal impact of relevant information. *See id.* at 1636.

[19]755 ILCS 40/20(c).

[20]*Ficke v. Evangelical Health Sys.*, 285 Ill. App. 3d 886, 893, 674 N.E.2d 888, 892 (3d Dist. 1996).

[21]755 ILCS 40/20(c). One commentator has argued that a surrogate should be consulted whenever the patient "may lack capacity." Rebecca J. O'Neill, *Surrogate Health Care Decisions for Adults in Illinois - Answers to the Legal Questions That Health Care Providers Face on a Daily Basis*, 29 LOY. U. CHI. L.J. 411, 423 (1998). But, as the Act states, the doctor must be reasonably certain that the patient actually lacks capacity or consulting a surrogate may violate patient privacy interests. The same commentator would limit surrogacy to "necessary" treatments, *id.*, but that is ambiguous and unduly narrow.

[22]755 ILCS 40/20(c).

applicable advance directive, like a living will or health care power of attorney.[23] Absent such a document, which this article assumes,[24] the doctor must next inquire as to the availability of individuals in the top four levels of a surrogate decision maker hierarchy: (1) the patient's guardian of the person; (2) the patient's spouse; (3) any adult daughter or son of the patient; and (4) either parent of the patient.[25]

Assume in the hypothetical that there is no court-appointed guardian and the patient's husband is easily accessible. If the patient lacks capacity, the doctor can generally rely on a treatment decision made by the husband unless that decision is "clearly contrary to [the] Act."[26] The Act instructs that "[a] surrogate decision maker shall make decisions for the patient conforming as closely as possible to what the patient would have done or intended under the circumstances . . . . If the adult patient's wishes are unknown . . . , the decision shall be made on the basis of the patient's best interests as determined by the surrogate decision maker."[27] This two-prong test—substituted judgment then best interests—corresponds to the two values at stake in medical decision making:

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[23] *Id.* § 25(a).

[24] This assumption is reasonable: "Population-based estimates of completed advance directives range from 5% to 15%." Sharda D. Ramsaroop et al., *Completing an Advance Directive in the Primary Care Setting: What Do We Need for Success?*, 55 J. AM. GERIATRICS SOC'Y 277, ___ (2007); *see also* Jeffrey Swanson et al., *Psychiatric Advance Directives Among Public Mental Health Consumers in Five U.S. Cities: Prevalence, Demand, and Correlates*, 34 J. AM. ACAD. PSYCHIATRY L. 43, 54 (2006) (4%-13% had completed psychiatric advance directives).

[25] 755 ILCS 40/25(a)(1)-(4). The rules, including surrogate priority, are the same under Unif. Health-Care Decisions Act § 5.

[26] 755 ILCS 40/30(a). At least one commentator has suggested that this transfer of decision making authority to a surrogate violates due process. O'Neill, *supra* note 21, at 428. I am aware of no successful challenge to a surrogacy act on these grounds. To the contrary, the Indiana Supreme Court squarely rejected such a challenge. *See Matter of Lawrance*, 579 N.E.2d 32, 42 n.8 (Ind. 1991) (surrogacy statute did not convert family decision into state action for due process purposes).

[27] 755 ILCS 40/20(b-5)(1). This is in accord with Unif. Health-Care Decisions Act § 5(f).

self-determination, generally first, and well being, generally second.[28] Another instance in which the doctor cannot rely on the surrogate is if the patient "objects" to the surrogate or any decision made by the surrogate.[29]

Suppose the husband's lone objection is that his wife is afraid of needles. The doctor should pause twice before accepting this decision: (1) the doctor cannot rely on the husband's decision if it is clear that the patient would set aside her fear of needles—*i.e.*, the decision would be "clearly contrary" to the Act's substituted judgment rule; and, more fundamentally, (2) the patient's assent arguably constitutes an objection to her husband's decision, which would negate operation of the Act. Either way, the doctor is left with no one having authority to consent to treatment and, without a trip to court, can transfuse only at peril of an action for medical battery. It is important to emphasize that the second reason for pause—the patient's objection—applies no matter how good the justification for the surrogate's decision. Suppose instead of a needle phobia, the husband had said that his wife was a devout Jehovah's Witness and could therefore not accept a blood transfusion. Her assent, albeit in a incapacitated state, would nonetheless stand as an objection to her husband's decision.

Of course, if the husband consents to the blood transfusion, then the doctor is on sturdier footing. Unless the doctor knows the patient would refuse the transfusion, such that treatment would be clearly contrary to the statutory substituted judgment rule of decision making, or the doctor has other reason to think the husband is thwarting the Act, she can safely rely on the husband's consent.

B. Hypothetical (2): Delusional Patient—Antipsychotic Medication

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[28]Allen Buchanan & Dan W. Brock, *Deciding for Others*, 64 MILBANK QUARTERLY 17 (Supp. 2 1986).

[29]755 ILCS 40/20(c). This is consistent with the law in other states. Mass. Gen. L. ch. 201D, § 6 (West 2008); N.Y. Pub. Health L. § 2983(5) (West 2008); Cal. Prob. Code § 4689 (West 2007).

As above, the doctor should assess capacity to satisfy her ethical duty with respect to informed consent and to avoid a claim of medical battery. In this scenario, there is a third source of this duty, the Mental Health and Developmental Disabilities Code (the "Code"), which mandates disclosure of risks and benefits of psychotropic medication or electro-convulsive therapy ("ECT") and compels the doctor to "determine and state in writing whether the recipient has the capacity to make a reasoned decision about the treatment."[30] This language appears in a section of the Code, 2-102, that also speaks about duties of "the facility," which could give rise to an inference that the section is limited to the inpatient setting. That reading, however, is belied by the very next two sections which expressly limit their scope to recipients "who reside[]in a mental health . . . facility."[31] Section 2-102 includes no such limitation.[32]

If the doctor finds capacity, she will again accept the patient's consent and order treatment. If the doctor finds a lack of capacity, her road diverges sharply from the blood transfusion case. A surrogate decision maker, other than a court appointed guardian, may not consent to the administration of psychotropic medication or ECT.[33] Assume that the patient's only adult child is

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[30]405 ILCS 5/2-102(a-5). I am aware of no comparable provision in California, Massachusetts, or New York.

[31]*Id.* §§ 2-103, 2-104.

[32]To the contrary, section 2-102 uses the unmodified word "recipient," which is defined to include, *inter alia*, any person who has received or is receiving "treatment." *Id.* § 1-123. "Treatment," in turn, expressly covers "outpatient services." *Id.* § 1-128.

[33]755 ILCS 40/60(a), (b); 405 ILCS 5/1-121.5. At least 10 other states and the District of Columbia exclude some mental health care from their surrogate decision making statutes. Alaska Stat. § 13.52.030(a) (West 2007); Ariz. Rev. Stat. Ann. § 36-3231(E) (West 2007); Cal. Welf. & Inst. Code § 5325 (West 2008); D.C. Code 1981 § 21-2211 (West 2008); Fla. Stat. Ann. § 765.113(1) (West 2007); Me. Rev. Stat. Ann. tit. 18-A, § 5-805 (West 2008); Md. Health-Gen. Code Ann. § 5-605(d)(2) (West 2008); Miss. Code Ann. §§ 41-41-227 (West 2007); N.M. Stat. Ann. 1978 § 24-7A-13 (West 2008); N.D. Cent. Code § 23-12-13(4) (West 2008); Va. Code § 54.1-2986(C) (West 2008).

available and consents to administration of psychotropic medication. That consent is meaningless under the clear terms of the Act and Code. The non-guardian surrogate's power to *refuse* treatment, no matter how good the reason (*e.g.*, a severe adverse reaction in the past to the particular medication proposed), is also questionable. The most specific statutory provision on this point, in the Code, limits the right to refuse medication to "[t]he recipient and the recipient's guardian or substitute decision maker."[34] "Substitute decision maker" is defined to include only individuals appointed in advance directives, not by operation of the Act.[35]

The doctor needs authority from somewhere other than the patient or patient's surrogate. There are two options: guardianship or a mental health treatment petition under the Code. Guardianship is rarely used in the mental health context, perhaps because a guardian has no authority to override a patient's treatment refusal.[36] Other reasons guardianship is not used may be that it is a time-consuming process and it is relatively permanent, whereas mental health treatment can often restore capacity. Any person over 18 years of age can file a mental health treatment petition.[37] Subject to certain continuances, the court must hold a hearing within 7 days of the filing of the petition.[38] To authorize treatment, the court must find 7 factors by clear and convincing evidence, including that the recipient lacks capacity and that the benefits of treatment outweigh the harm.[39]

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[34]405 ILCS 5/2-107(a).

[35]*Id.* § 1-110.5.

[36]*Id.* § 2-107.1(b).

[37]*Id.* § 2-107.1(a-5)(1).

[38]*Id.* § 2-107.1(a-5)(2).

[39]*Id.* § 2-107.1(a-5)(4).

C. Hypothetical (3): Manic Patient—Hospitalization

Again, the doctor should first assess capacity. There is no specific statutory requirement to do so,[40] unlike with psychotropic medication and ECT. There is, however, United States Supreme Court case law strongly suggesting that due process requires some assessment of capacity at least in state-run facilities. In *Zinermon v. Burch*, a patient complained that his voluntary admission to a psychiatric facility when he lacked capacity to give informed consent deprived him of liberty without due process of law.[41] The Court decided the case on a technical ground, expressly indicating that it was not deciding what the Constitution required in such cases.[42] The Court did, however, state that the patient's five-month confinement, with no hearing or other procedure to determine the validity of consent or whether the patient met the standard for involuntary placement, "clearly infringes on [the] liberty interest" in avoiding confinement in a mental hospital.[43]

If the doctor finds capacity, the patient can consent to voluntary admission. If the doctor finds incapacity, reliance on surrogate consent is expressly prohibited.[44] A surrogate may, however, petition for involuntary admission.[45] But the grounds for voluntary and involuntary admission are different. Involuntary admission requires that the patient be "in such a condition that immediate

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[40]In this respect, Illinois is like most states. *See* Winick, *supra* note 1, at 178 n.59.

[41]494 U.S. 113, 114-15 (1990).

[42]*Id.* at 117.

[43]*Id.* at 131.

[44]405 ILCS 5/3-601.2. In this, Illinois is like many other states. *See* Fla. Stat. Ann. § 765.113(1); Me. Rev. Stat. Ann. tit. 18-A, § 5-805; Miss. Code Ann. § 41-41-227(5); N.M. Stat. Ann. 1978, § 24-7A-13(E); N.D. Cent. Code § 23-12-13(4); Va. Code § 54.1-2986(C).

[45]*Id.*

hospitalization is necessary for the protection of such person or others from physical harm."[46] In contrast, voluntary admission is allowed on the broader and more discretionary ground that "the facility director deems [the patient] clinically suitable for admission as a voluntary recipient."[47] Some incapacitated patients who could benefit from hospitalization (and would consent to it if competent) may not be immediately dangerous and therefore could not be admitted either voluntarily or involuntarily. Plainly, there is potential for some individuals to fall between the cracks.[48]

If the incapacitated bipolar man in the hypothetical is dangerous to himself or others, any person 18 years or older, including the facility director, may file a petition for involuntary admission.[49] The petition generally must be accompanied by a certificate executed by a mental health professional relaying clinical observations based on an examination made not more than 72 hours prior to admission.[50] Within 24 hours of admission the facility director must file the petition and certificate in court, and a hearing must be scheduled within 5 days thereafter.[51] If the incapacitated man presents no immediate danger to himself or others, he cannot be admitted, despite his willingness to sign a consent form, his surrogate's concurrence, and his need for admission on any ground other than dangerousness.

D. Sources of the Disconnect Between Law and Practice

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[46] *Id.* § 3-601 (a).

[47] *Id.* § 3-400.

[48] *See* Francine Cournos et al., *Report of the Task Force on Consent to Voluntary Hospitalization*, 21 BULL. AM. ACAD. PSYCHIATRY L. 293, 293 (1993) ("not every patient who could benefit significantly from voluntary hospitalization will meet the more restrictive requirements for involuntary hospitalization"). This gap exists in many states other than Illinois.

[49] *Id.* § 3-601(a).

[50] *Id.* § 3-602.

[51] *Id.* § 3-611.

Doctors fail to test the capacity of assenting patients for several reasons. Probably the strongest force at work is doctors' overriding goal of beneficence. The doctor has already determined that treatment is in the patient's best interests. If the patient does not resist, the overwhelming pull is toward treatment. The "asymmetric sliding scale," discussed *infra* Subsection III.B.1, also tilts against testing, because it sets the capacity bar low where the patient makes the "right" decision. The next contributing cause is the presumption of capacity. Few doctors may be aware that a legal presumption of capacity exists, but they no doubt operate consistent with the presumption and their lawyers would be requiring capacity forms along with informed consent forms if the presumption did not exist. A related factor is the absence of any enforced legal requirement to test capacity. To be sure, Illinois technically requires capacity testing before administration of psychotropic medications or ECT, but there is no enforcement provision or penalty.[52] With voluntary hospitalization, apart from *Zinermon*'s dicta, there is no requirement even on paper. A final cause of the failure to test capacity is the high cost of an incapacity finding. This applies most strongly in the mental health context, where a lack of capacity always requires a trip to court, but it also applies whenever patient and surrogate disagree in non-mental health settings.[53]

III. NEW MODEL

This section outlines and defends an alternative model of health care decision making for the situation in which a patient with dubious capacity assents to treatment. Specifically, the model

[52]On the other hand, tort liability is possible. *Threlkeld v. White Castle Sys.*, 205 F. Supp. 2d 935, 937 (N.D. Ill. 2002).

[53]Prohibiting surrogate decision making appears to cause assessors to lower the capacity threshold where testing is required. Scott Y.H. Kim et al., *Proxy and Surrogate Consent in Geriatric Neuropsychiatric Research: Update and Recommendations*, 161 AM. J. PSYCHIATRY 797, 803 (2004). Where testing is optional, it seems likely to suppose that physicians would test capacity less if surrogate decision making were unavailable.

addresses when to test capacity, how to test capacity, and what to do when capacity is lacking. Because the first question (when to test) turns on the accuracy of the test (how to test) and the accuracy of alternative decision making (what to do if incapacity), the three issues are discussed in reverse order.

A. What to Do When the Patient Lacks Capacity

When a patient lacks capacity someone else must make the decision for him.[54] The candidates are: (1) the doctor, (2) the statutory surrogate, (3) an appointed proxy, (4) a guardian, or (5) a court. Because doing so most directly promotes self-determination, a proxy designated in an advance directive or health care power of attorney should be given priority.[55] If a guardian with power over health care has already been appointed, the formal process through which this occurred would seem to put the guardian next in line. Going to court anew in every case either to appoint a guardian or to decide a treatment question would squander precious treatment time and overburden the courts.[56] Absent a proxy or guardian, this leaves the doctor and statutory surrogate as the viable first-line decision makers. In current practice, especially in mental health, treatment decisions are often left entirely to the doctor's discretion if the patient assents. Surrogates would do better.

A recent review of 16 studies found that surrogates predicted patients' treatment preferences

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[54]This assumes reasonable efforts to improve capacity have failed. Research has demonstrated the effectiveness of such efforts. Scott Y.H. Kim et al., *Current State of Research on Decision-Making Competence of Cognitively Impaired Elderly Persons*, 10 AM. J. GERIATRIC PSYCHIATRY 151, 162 (2002); David J. Moser et al., *Using a Brief Intervention to Improve Decisional Capacity in Schizophrenia Research*, 32 SCHIZOPHRENIA BULL. 116 (2005).

[55]This is already the rule in Illinois at least. *In re Schmidt*, 298 Ill. App. 3d 682, 692, 699 N.E.2d 1123, 1130 (2d Dist. 1998).

[56]1 PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE & BIOMEDICAL & BEHAVIORAL RESEARCH, MAKING HEALTH CARE DECISIONS: THE ETHICAL AND LEGAL IMPLICATIONS TO THE PATIENT-PRACTITIONER RELATIONSHIP 175, 185 (1982)

with 68% accuracy.[57] The reviewers concluded that the "data undermine the claim that reliance on surrogates is justified by their ability to predict incapacitated patients' treatment preferences."[58] But surrogates did significantly better than chance: the lower bound of the 95% confidence interval on the 68% figure was 63% (the upper bound was 72%), well above the 50% one might expect from a coin toss.[59] Furthermore, in scenarios more closely approximating an actual treatment decision, the 68% figure rose significantly: surrogates correctly predicted patients' preferences in 79% of scenarios involving the patient's current health (95% CI, 74%-83%).[60] On the other hand, surrogates were least accurate in scenarios involving dementia (58%; 95% CI, 52-64), the one mental health condition summarized in this review.[61] Finally, and most important for present purposes, "[f]our additional studies confirmed that surrogates predict patients' preferences more accurately than do physicians."[62] Those four studies covered 15 hypothetical treatment scenarios; surrogates were more accurate than doctors in 14 out of 15.[63]

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[57]David I. Shalowitz et al., *The Accuracy of Surrogate Decision Makers: A Systematic Review,* 166 ARCH. INTERN. MED. 493, 493 (2006).

[58]*Id.*

[59]*Id.* at 495.

[60]*Id.*

[61]*Id.* at 495. One might wonder how we can know the preferences of demented patients. The finding reported in the text did not need to address that issue because although the scenarios involved dementia, the patients surveyed were not demented.

[62]*Id.* at 496.

[63]Joseph G. Ouslander et al., *Health Care Decisions Among Elderly Long-term Care Residents and Their Potential Proxies*, 149 ARCH. INTERN. MED. 1367 (1989); K. Principe-Rodriguez et al., *Substituted Judgement: Should Life-Support Decisions Be Made By a Surrogate?*, 18 P.R. HEALTH SCI. J. 405 (1999); Allison B. Seckler et al., *Substituted Judgment: How Accurate Are Proxy Predictions?*, 115 ANN. INTERN. MED. 92 (1991); Richard F. Uhlmann et al., *Physicians' and Spouses' Predictions of Elderly Patients' Resuscitation Preferences*, 43 J. GERONTOLOGY M115 (1988).

One of those four studies, like the second hypothetical in this article, involved psychotropic medication.[64] Patients' closest relatives correctly predicted whether the patient would take a sleeping pill with 61% accuracy (n=36); physicians chose the same decision as the patient in 43% of cases (n=53).[65] Despite the small sample sizes, this difference approached marginal statistical significance (p=0.10). In sum, surrogates do better than chance and better than doctors at predicting patient preferences.[66]

It would be a mistake, however, to put too much faith in the surrogate accuracy numbers found in the 16-study review. First, 90% of the 151 scenarios involved interventions necessary to save or sustain the patient's life.[67] Most health care decisions are not potentially fatal, so research on more representative scenarios is needed. Second, and related, it is likely that investigators in the underlying studies designed their hypotheticals to present difficult treatment decisions. They would do so to avoid ceiling effects. If 99% of patients would choose a particular treatment alternative, one would expect the surrogates to recognize this and to have a very low error rate. One study supports this claim: 84% of patients chose vaccination in one of four clinical vignettes; surrogate accuracy was much higher in this vignette (78%) than in the other three (64% mean), which presented closer calls.[68]

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[64]Ouslander et al., *supra* note 63.

[65]*Id.* at 1370 tbl.2.

[66]The review also provides some reason to think that statutorily designated surrogates may do as well as court-appointed guardians. Patient-designated surrogates predicted patients' preferences no better than legally assigned surrogates. Shalowitz et al., *supra* note 57, at 496. If the patient himself cannot select someone who will do better than the statutory default surrogate, then how can we expect a court to?

[67]*Id.* at 494.

[68]Ouslander et al., *supra* note 63, at 1369 tbl.1, 1370 tbl.2.

There are reasons to question whether a patient's answer to a hypothetical question is an accurate gauge of the patient's preference should the situation arise. Preferences change over time. In one study, about one quarter of AIDS patients presented with hypotheticals regarding life-extending treatment changed their minds after four months.[69] A meta-analysis concluded that "over periods as short as two years, almost one-third of preferences for life-sustaining medical treatment changed."[70] To the extent patient preferences are a moving target, this presumably reduces surrogate accuracy below what a snapshot in time would suggest.

It is important to note that there is a disconnect between the surrogate accuracy studies and what surrogates are actually asked to do. Illinois is not alone in its two-tier standard for surrogate decision making: substituted judgment first and best interests second.[71] There is no gold standard for best interests, so surrogate performance on this measure is impossible to test. Instead, surrogates in accuracy studies are told to predict patient preferences even if that means just guessing. Presumably, surrogate accuracy in the studies would increase if their predictions were limited to instances in which they believed they knew how the patient would decide the question.

That would, of course, leave decisions in which there is no indication as to what the patient would want (making substituted judgment impossible to apply). Why prefer family members to make decisions here? The best interests standard in this context is subjective, not objective. In weighing relevant benefits and burdens, surrogates in Illinois are instructed to "take into account any

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[69]Jeremy A. Blumenthal, *Law and the Emotions: The Problems of Affective Forecasting*, 80 IND. L.J. 155, 220 (2005) (citing Joel S. Wessman et al., *The Stability of Preferences for Life-Sustaining Care Among Persons with AIDS in the Boston Health Study*, 19 MED. DECISION MAKING 16 (1999)).

[70]Angela Fagerlin & Carl E. Schneider, *Enough: The Failure of the Living Will*, 34 HASTINGS CENTER REP. 30, 34 (Mar.-Apr. 2004).

[71]Uniform Health-Care Decisions Act § 2(e) (1994).

other information, including the views of family and friends, that the surrogate decision maker believes the patient would have considered if able to act for herself or himself."[72] Family members generally know the patient best and are therefore best positioned to know what factors the patient would have considered, even if they do not know what decision the patient would have made.[73]

Allowing family members to decide when there is no guidance on the patient's treatment preference appears to be what patients want. In one study of research choices among older individuals, "[a]lthough a clear majority (80.9%) preferred to give advance instructions rather than have their family members decide (12.6%), 87.8% also responded that their family members may consent for them if no advance directive exists."[74] A commentator summarized similar findings from other studies: "an overwhelming majority (approximately ninety percent) of citizens . . . prefer that family members serve as health care proxies . . . ."[75] There are other reasons to favor decision

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[72]755 ILCS 40/20(b-5)(1).

[73]Jennifer L. Wright, *Protecting Who from What, and Why, and How?: A Proposal for an Integrative Approach to Adult Protective Proceedings*, 12 ELDER L.J. 53, 90-91 (2004).

Closeness of relationship rather than family tie might be a better selection criterion, but closeness of relationship is hard to measure. "[R]elational proximity is more difficult for physicians and judges to confirm than familial proximity, thus the latter is taken as a surrogate for the former. As a matter of policy this seems to be the most efficient course." Jonathan D. Moreno, *Who's to Choose? Surrogate Decisionmaking in New York State*, 23 HASTINGS CENTER REP. 5, 7 (1993)

[74]Scott Y.H. Kim et al., *Proxy and Surrogate Consent in Geriatric Neuropsychiatric Research: Update and Recommendations*, 161 AM. J. PSYCHIATRY 797, 801 (2004). There is some indication that psychiatric patients may have different preferences. *See* Debra S. Srebnik, *The Content and Clinical Utility of Psychiatric Advance Directives*, 56 PSYCHIATR. SERV. 592, 596 (2005) ("Just under half of the sample (46 percent) [of individuals with severe and persistent mental illnesses in Washington state in 2001-2003] appointed a surrogate decision maker. Most often friends were listed, followed by parents, siblings, spouses, and children."). Further research on surrogate preferences is needed.

[75]Alison Patrucco Barnes, *The Randolph W. Thrower Symposium: Elder Law: Beyond Guardianship Reform: A Reevaluation of Autonomy and Beneficence for a System of Principled Decision-Making in Long Term Care*, 41 EMORY L.J. 633, 686 (1992).

making by family members: "family members will be most affected by decisions, the patient excepted; . . . justice requires consideration of the effects on family; and . . . the family is a moral unit with responsibility for its members."[76]

Surrogate decision making may also lead to more accurate capacity testing. In one large study, sites where surrogate decision making was prohibited reported much lower rates of incapacity than sites allowing for surrogates.[77] Given that the study involved sufferers of Alzheimer's Disease with low MMSE scores, the very low levels of incapacity at the no-surrogacy sites are suspicious.[78] This suggests that there is a powerful disincentive to finding incapacity if there is no surrogate decision making structure in place.

Introducing a surrogate may advance patient well being as well as autonomy. Research shows that patients without decision making capacity are less likely to receive treatment consistent with the standard of care than patients with decision making capacity.[79] Given how common it is to treat assenting incompetent patients without consulting surrogates, this finding suggests that the involvement of a second competent decision maker in addition to the doctor can improve the quality of medical care. It is not surprising that collaborative decision making should achieve better outcomes.

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[76]Jeffrey T. Berger, *Patients' Interests in their Family Members' Well-Being: An Overlooked, Fundamental Consideration within Substituted Judgments*, 16 J. CLIN. ETHICS 3, 4 (2005) (citing Dan W. Brock, *What is the Moral Authority of Family Members to Act as Surrogates for Incompetent Patients?*, 74 MILBANK QUARTERLY 599 (1996)).

[77]Scott Y.H. Kim et al., *Proxy and Surrogate Consent in Geriatric Neuropsychiatric Research: Update and Recommendations*, 161 AM. J. PSYCHIATRY 797, 803 (2004).

[78]*See id.* (MMSE from 13 to 26 inclusive; 0% to 15% incapacity).

[79]S.K. Hoge & T.C. Feucht-Haviar, *Long-term, Assenting Psychiatric Patients: Decisional Capacity and the Quality of Care*, 23 BULL. AM. ACAD. PSYCHIATRY & L. 343 (1995).

To be sure, there may be problems with relying on family members. "[T]here is a high prevalence of elder abuse and exploitation by strangers, friends, and family members."[80] "[D]isturbed patients not infrequently come from disturbed families in which no available family member possesses sufficient capacity to grasp the complexities of major decisions."[81] Family dysfunction and conflicts of interest would seem especially likely among the mentally ill. However, "[w]hile it may be argued that permitting family members or close friends to make medical decisions on behalf of another without judicial approval has the potential for abuse, 'the evidence for such abuse is all but nonexistent, and the health care system would slip into paralysis if it had to delay treatment of the large percentage of severely ill patients who are incompetent until a court hearing could be obtained.'"[82]

When an assenting patient lacks capacity, the statutory surrogate—any patient-appointed proxy, then court-appointed guardian, followed by family members in descending closeness of relation,[83] then close friends—should make medical treatment decisions, including decisions regarding psychotropic medication and voluntary hospitalization.[84] This would also include the

[80]Jennifer Moye & Daniel C. Marson, *Assessment of Decision-Making Capacity in Older Adults: An Emerging Area of Practice and Research*, 62B J. GERONTOLOGY P4 (2007).

[81]PAUL S. APPELBAUM & THOMAS G. GUTHEIL, CLINICAL HANDBOOK OF PSYCHIATRY AND THE LAW 205 (4th ed. 2007).

[82]Halverson, *supra* note 13, at 167 (quoting GUTHEIL & APPELBAUM, *supra* note 13, at 226).

[83]Although the exact priority list is outside the scope of this article, spouse would seem to belong on top of the familial hierarchy and should include same-sex partner. *E.g.*, N.M. Stat. Ann. 1978 § 24-7A-5(B)(2).

[84]I am certainly not the first to make this proposal. *E.g.*, Halverson, *supra* note 13; Michael Irwin et al., *Psychotic Patients Understanding of Informed Consent*, 142 AM. J. PSYCHIARTY 1351, 1354 (1985). It is already the law in many states.

power to overrule the incapacitated patient's assent to treatment.[85]

Because of the possibility of abuse, especially among the mentally ill, three additional protections are needed. First, a patient who continues to assent to treatment after being informed of his surrogate's treatment refusal should have the right to insist on a second opinion regarding capacity. That opinion should be rendered, where possible, by a health care professional not involved in the patient's treatment and not subordinate to someone who is. Even with relatively low capacity test accuracy, repeat testing can substantially improve confidence in an incapacity finding.[86] Second, if the doctor believes that the surrogate has clearly failed to respect the patient's expressed wishes or, where the patient's wishes are unknown, to advance the patient's best interests, then the doctor ought to be able to petition the court for a treatment decision or appointment of a guardian.

The third protection applies to voluntary admission for psychiatric care. In Illinois, a patient who is voluntarily admitted must be discharged within 5 days of giving written notice of his desire to be discharged unless within that period an involuntary petition is filed.[87] The petition must be accompanied by 2 certificates from a physician, qualified examiner, or clinical psychologist stating that the patient is subject to involuntary admission and requires immediate hospitalization.[88] Hearing on that petition must take place within 5 days of the filing of the petition.[89] Thus, a voluntarily admitted patient can go 10 days before getting a hearing on the appropriateness of

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[85]This would require a change in Illinois law, *see supra* text accompanying and following note 29, as well as the laws of several other states. *E.g.*, Mass. Gen. L. ch. 201D, § 6; N.Y. Pub. Health L. § 2983(5); Cal. Prob. Code § 4689.

[86]*See infra* note 180.

[87]405 ILCS 5/3-403.

[88]*Id.*; 405 ILCS 5/3-602.

[89]405 ILCS 5/3-403.

hospitalization. The 2 certificate requirement renders the second 5 days somewhat less objectionable, but the initial 5-day period is troubling.

If a patient had capacity and understood the 5-day holding period when he executed the voluntary admission form, then there would be less need to protect his change of mind. Under my proposal, however, an incapacitated patient could be admitted on a "voluntary" basis through the consent of a surrogate. Such a patient almost certainly had no understanding of the 5-day period. Should the patient become capacitated, 5 days is much too long to wait for release. A patient admitted by a surrogate should have the right to a second opinion within 24 hours as to capacity and the appropriateness of hospitalization. The second opinion should come from a health care professional not involved in the patient's treatment and not under the supervision of anyone who is. If this professional finds capacity or release otherwise appropriate, the facility should be required immediately either to release the patient or to start involuntary admission proceedings.

B. How to Assess Capacity

The previous subsection argued that familial surrogates should generally make treatment decisions for patients who lack capacity. This subsection examines the question of how one ought to assess capacity. The appropriateness of a moving threshold of capacity, or "sliding scale," is discussed first, followed by an argument that capacity testing should be based on standardized instruments, not discretionary judgment.

1. Sliding Scale

It is generally accepted that more exacting capacity scrutiny is merited for certain decisions. There are at least three variations on this theme: (1) a higher threshold for capacity is needed when a patient refuses treatment than when a patient accepts treatment because treatment is the benefit-cost

justified choice;[90] (2) capacity testing is appropriate when a patient refuses treatment, but not necessary when the patient accepts treatment, because base rate incapacity is higher among treatment refusers;[91] and (3) a higher threshold for capacity is needed when the treatment decision presented is complicated or high-stakes than when the decision is simple and low-stakes.[92] Note that the first and second variations are asymmetric between refusal and acceptance, whereas the third version sets the capacity threshold based on the decision presented, not the choice made. For reasons that will become clear, I will refer to these three variations, respectively, as the asymmetric sliding scale, the sliding screen, and the symmetric sliding scale.

The rationale usually provided for the asymmetric sliding scale is it "takes into account the greater harm that may follow from the failure to accept necessary medical care."[93] But greater than what? Greater than the harm that may follow from refusing optional rather than necessary medical care? No, this would justify the symmetric sliding scale, but not the asymmetric version. The comparison must instead be between treatment and non-treatment—specifically, treatment over

[90]Cathy A. Klein, *Decision-Making Capacity and Informed Consent*, 30(2) NURSE PRACTITIONER 12 (2005) ("A patient may have the capacity to consent to an intervention, but may lack the capacity to refuse it."); APPELBAUM & GUTHEIL, *supra* note 81, at 184. If the benefit-cost ratio is unfavorable, there is a high capacity threshold for acceptance and low threshold for refusal. Loren H. Roth et al., *Tests of Competency to Consent to Treatment*, 134 AM. J. PSYCHIATRY 279, 283 tbl.1 (1977).

[91]Klein, *supra* note 90, at 12 ("If a patient makes a decision that the [Nurse Practitioner] considers unreasonable, further investigation into the patient's capacity is necessary.").

[92]1 PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE & BIOMEDICAL & BEHAVIORAL RESEARCH, MAKING HEALTH CARE DECISIONS: THE ETHICAL AND LEGAL IMPLICATIONS TO THE PATIENT-PRACTITIONER RELATIONSHIP 55, 60 (1982) (decision making capacity does not depend "on the decision reached," but greater capacity may be required where "the consequences for well-being are substantial").

[93]Francine Cournos et al., *Report of the Task Force on Consent to Voluntary Hospitalization*, 21 BULL. AM. ACAD. PSYCHIATRY L. 293, 301 (1993).

objection versus respecting the objection. The harm of treatment over objection is, if the patient has capacity, an infringement on patient autonomy. The harm of failing to treat an objecting patient is whatever health consequences follow. Implicit in the asymmetric sliding scale is a judgment that patient well being, as determined by the treating physician, sometimes outweighs patient autonomy.

This same tradeoff is at issue when the patient accepts treatment. The doctor can either accept assent at face value or examine the patient's capacity, thereby risking treatment refusal by the surrogate (or court). If treatment is strongly justified by benefit-cost analysis, the asymmetric sliding scale would put the capacity bar so low that detailed capacity assessment is unnecessary. The patient who expresses the "right" choice will almost always be deemed to have capacity. Proposed guidelines for voluntary admission are illustrative. After the Supreme Court's decision in *Zinermon*, there was real concern that the practice of voluntary admission might be in trouble. One response was to lower the capacity threshold for voluntary admission to require: "communicating choices and understanding relevant information."[94] The relevant information included: (1) that the patient was being admitted to a psychiatric hospital for treatment; and (2) that release may not be automatic.[95] With this limited amount of information, almost no sane person would agree to admission. He would insist at a minimum on knowing the terms and conditions governing release.

As California has already done,[96] all states should outlaw the asymmetric sliding scale. Doctors should not have the right to trade off autonomy and well being in setting the capacity threshold. Whether a patient has capacity should not depend on the choice made, but only on the

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[94] *Id.* at 300.

[95] *Id.* at 304.

[96] *See* Cal. Probate Code § 813(b) ("A person who has the capacity to give informed consent to a proposed medical treatment also has the capacity to refuse consent to that treatment.").

patient's ability to make the choice. Competent patients have an unqualified right to make decisions that their doctors think unwise.[97] The asymmetric sliding scale "conflates the determination of capacity and justified paternalistic interventions, or the determination of capacity and the normative evaluation of outcome."[98] A defense of the asymmetric sliding scale that on its surface appears more compelling is a desire to avoid erroneous failures to treat.[99] But this defense ultimately depends on weighing failures to treat more heavily than failures to respect autonomy.[100] If errors are particularly costly for certain treatment decisions, a symmetric solution is to test capacity more than once rather than placing a thumb on the scale to favor treatment.[101]

More exacting capacity scrutiny along these lines is parallel to the sliding screen. Although screening for treatment refusers is generally justified as balancing between autonomy and beneficence, the discussion below of whom to test for capacity demonstrates that a symmetric desire to minimize treatment errors can justify asymmetric screening if the data show a substantial difference in base rate incapacity between refusers and acceptors.[102] More research is needed.

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[97] *Lane v. Candura*, 376 N.E.2d 1232, 1236 (Mass. App. 1978).

[98] M. Parker, *Competence by Consequence: Ambiguity and Incoherence in the Law*, 25 MED. L. 1, 8 (2006). For additional arguments against the sliding scale and a proposed 3-tiered alternative, see Elyn R. Saks & Dilip V. Jeste, *Capacity to Consent to or Refuse Treatment and/or Research: Theoretical Considerations*, 24 BEHAV. SCI. L. 411, 422-23 (2006).

[99] Alec Buchanan, *Mental Capacity, Legal Competence and Consent to Treatment*, 97 J. ROYAL SOC'Y MED. 415 (2004).

[100] *See* Parker, *supra* note 98, at 8 ("if we raise the level of competence in order to avoid mistakes, we simultaneously increase the risk of overriding competent voluntary choices").

[101] *See* Gita S. Cale, *Risk-Related Standards of Competence: Continuing the Debate Over Risk-Related Standards of Competence*, 13 BIOETHICS 131, 148 (1999) ("While the risks related to a decision might be grounds for taking more care in assessing a person's competence, they should not provide grounds for increasing the standards by which a person's competence is assessed.").

[102] *See infra* Subsections III.C.1, 6.

There will need to be particular attention paid to the treatment decision at issue, since that will almost certainly have a large effect on observed incapacity levels.

This leaves variation number three: the symmetric sliding scale. This version is appropriate. Plainly, complex decisions require a greater level of understanding than simple ones, and weighty decisions demand more appreciation than trivial ones.[103] Allowing the capacity standard to vary in these ways is just a corollary of the principle that capacity is task-specific. Making decisions necessarily involves comparing alternatives. Understanding and appreciating both alternatives is required for meaningful decision making. The asymmetric sliding scale focuses on the perceived quality of one choice, the choice made, which improperly interjects physician value judgments. In contrast, the symmetric sliding scale considers the complexity and stakes of the choices presented, not the choice made. The focus is properly on the decision making process, not the result.

2. Standardized Instruments

Capacity should be assessed through formal standardized instruments, not through doctors' discretionary judgments. The primary reason is simple: "informal assessments performed by physicians are idiosyncratic and unreliable."[104] One study reported mere 56% agreement among unguided physician assessments of capacity.[105] A follow-up study by the same researchers employing specified legal standards and a standardized assessment tool found 76% agreement.[106]

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[103]On the distinction between understanding and appreciation, see *supra* note 18.

[104]Edward D. Sturman, *The Capacity to Consent to Treatment and Research: A Review of Standardized Assessment Tools*, 25 CLIN. PSYCH. REV. 954, 954 (2005).

[105]Daniel C. Marson et al., *Consistency of Physician Judgments of Capacity to Consent in Mild Alzheimer's Disease*, 45 J. AM. GERIATRICS SOC'Y 453, 453 (1997).

[106]Daniel C. Marson et al., *Consistency of Physicians' Legal Standard and Personal Judgments of Competency in Patients with Alzheimer's Disease*, 48 J. AM. GERIATRICS SOC'Y 911, 911 (2000). Standardized instruments may not be needed in the ICU, where high levels of

Worse, unguided physician judgments appear to be systematically biased. "[I]ncapacity may be more frequently diagnosed in treatment-refusers than in treatment-acceptors."[107] Comparisons of instrument-based and clinician ratings of capacity find that a significant proportion of patients are judged by physicians to have capacity but by instruments to lack capacity. "Notably, this rating discrepancy occurs most often with treatment-acceptors, implying a systematic rater bias with important ethical ramifications."[108] This pattern probably reflects use of the asymmetric sliding scale, which, as argued above, is inappropriate. The data suggest that instrument-based capacity assessment may help to overcome this bias.[109]

The downside of standardized instruments is time. The leading assessment tool, the MacCAT-T, requires substantial training and takes between 15-20 minutes to administer.[110] If, however, full capacity testing is limited to instances in which screening in relatively high incapacity base rate populations identifies problems, as proposed below, the costs will be mitigated to a large degree. Of course, training costs may still be substantial. Preliminary success with one screening instrument led researchers to conclude that "screening every patient for clinical competency is

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agreement in essentially unguided clinical judgments have been observed (89%). Lewis M. Cohen et al., *Do Clinical and Formal Assessments of the Capacity of Patients in the Intensive Care Unit to Make Decisions Agree?*, 153 ARCH. INTERN. MED. 2481, 2483 (1993).

[107]Jennifer Moye et al., *Empirical Advances in the Assessment of Capacity to Consent to Medical Treatment: Clinical Implications and Research Needs*, 26 CLIN. PSYCH. REV. 1054, 1064 (2006).

[108]*Id.* at 1069.

[109]The leading standardized instruments measure abilities with respect to the particular treatment decision at issue, which effectively (and appropriately) incorporates the symmetric sliding scale.

[110]Thomas Grisso et al., *The MacCAT-T: A Clinical Tool to Assess Patients' Capacities to Make Treatment Decisions*, 48 PSYCHIATRIC SERVICES 1415, 1416 (1997).

possible and economically feasible."[111]

Several factors are relevant in reaching this conclusion. The costs of administration and training are key, but those costs can be reduced not only by screening but also by shifting responsibility for testing away from doctors toward less costly health care professionals. A standardized instrument includes many steps without discretionary judgment, where there is little need for a doctor. Two primary benefits must be weighed against these costs: an increase in the true positive rate and decrease in the false positive rate. The inter-rater reliability numbers cited above are merely suggestive of these benefits, but strongly so. Given the very low inter-rater reliability of unguided discretionary judgment, it would appear that standardized instruments could generate substantial, cost-justified benefits.

C. When to Test for Capacity?

There are many possible answers to this question: never, always, before administering particular treatments, based on patient status (all inpatients, *e.g.*), for certain diagnoses or symptoms, whenever the patient makes the "wrong" decision, and based on a screening test. Illinois law requires capacity testing for two treatments: psychotropic medication and ECT. Does this requirement make sense? Should capacity testing be required more narrowly or broadly? And, if so, when? Reviewing the other possibilities for capacity testing and existing data on incapacity will help to answer these questions.

1. General Propositions

Never to test would make the presumption of capacity irrebutable. This would be warranted if no one were in fact incapacitated, or if the test for incapacity had no validity, or if the alternative

[111]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, 135 (1992).

decision making process were no better than letting an incapacitated patient decide. However, there are good reasons to think that all three of these propositions are false. Countless studies identify individuals who lack capacity. Although the quest for validity is plagued by the absence of a readily available gold standard, high inter-rater reliability and comparison to expert judgment suggest that standardized capacity assessment tools tend to meaningfully distinguish between those with and without capacity. And surrogates do better than chance in predicting patient preferences.

Testing every patient would obviously be very costly. Again, the leading assessment tool requires training and takes between 15-20 minutes to administer.[112] Setting cost to one side, the base rate of incapacity among all patients is almost certainly too low to justify testing everyone. Given reasonable assumptions about test validity and surrogate accuracy, it is possible to quantify this intuition.

Assume, consistent with the overriding objective of self-determination, that the goal of medical decision making is to minimize instances in which treatment deviates from a patient's true preference. Patients with capacity express their true preference 100% of the time; patients without capacity do no better than chance, stating their true preference 50% of the time.[113] (This assumes a binary choice, even though there may be more than one treatment option.) A capacity test can only distinguish between the two categories of patients with error. Assume that the probability of a positive incapacity test result given incapacity (sensitivity) is *x*. Assume further that the false

[112]Grisso et al., *supra* note 110, at 1416.

[113]Although capacity must necessarily be reduced to a yes-no outcome, it turns on continuous rather than dichotomous variables, so the assumptions of 100% and 50% are somewhat arbitrary. The 100% figure can be defended as true by definition: if a patient has capacity, then the preference they express is deemed to be their actual preference. The 50% figure is more arbitrary. It could be the case that some individuals without capacity make systematically bad (rather than random) choices. It is also quite likely that some individuals just below that capacity threshold do better than chance in expressing actual preferences. I take 50% as an admittedly arbitrary central tendency.

positive rate, the probability of a positive incapacity test given capacity, is *z*. If the patient tests positive for incapacity, the treatment decision will be made by a surrogate under a pure substituted judgment rule, with an accuracy rate of *s*. Let *y* be the prevalence or base rate of incapacity in the patient population.

The net effect of testing on treatment decisions is the number of treatment errors introduced due to false positives minus errors avoided due to true positives. When those two numbers are equal, testing is equivalent to not testing in terms of treatment errors. At a given level of surrogate accuracy, higher test accuracy and higher base rates will reduce treatment errors. The following equation, an application of Bayes' Rule,[114] shows the relationships among *x*, *y*, *z*, and *s* at the point of indifference between testing and not testing:

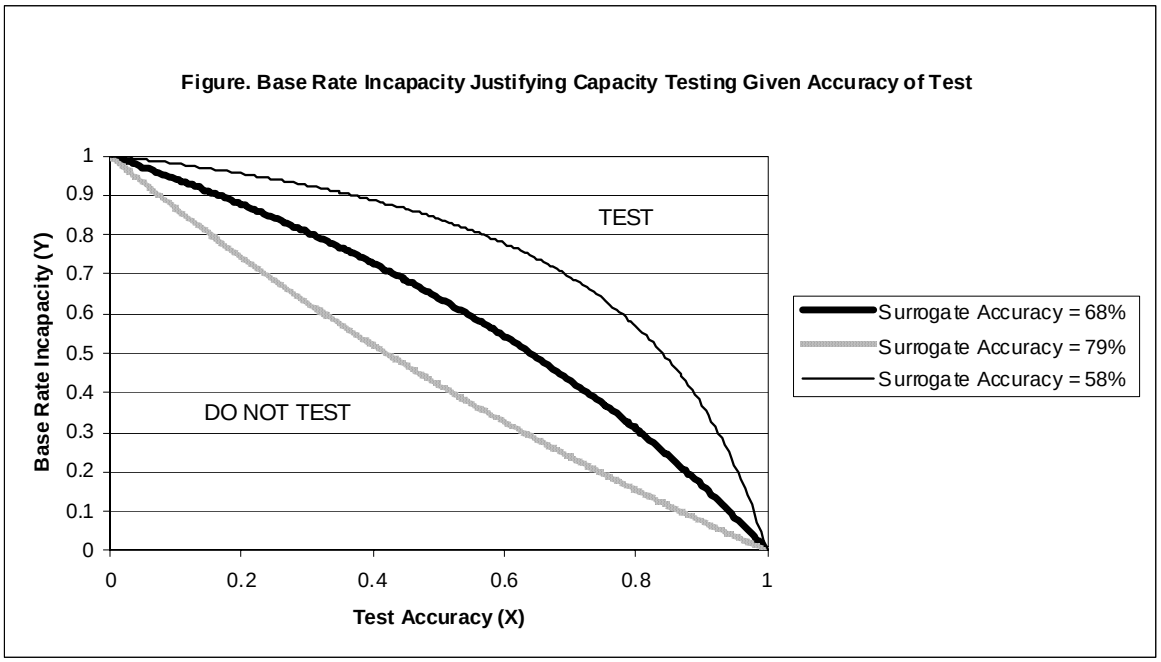
Equation. Threshold for Capacity Testing

$$\left[\frac{x * y}{x * y + z * (1 - y)}\right] * (s - 0.5) = \left[\frac{z * (1 - y)}{z * (1 - y) + x * y}\right] * (1 - s)$$

In words, the left side of the equation is the probability of a true positive multiplied by the improvement in decision making from substituting the surrogate for a patient without capacity. The right side is the false positive rate times the effect of shifting from perfect decision making to a flawed surrogate. When the effects of true positives and false positives are equal, testing and not testing produce equal numbers of treatment errors. The equation is therefore a formal representation of that indifference point (curve, actually).

[114]Bayes' Rule is "a result in probability theory" that "tells how to update or revise beliefs in light of new evidence." http://en.wikipedia.org/wiki/Bayes'_theorem (visited Oct. 17, 2007).

Recall that surrogate accuracy in a recent review of 16 studies was 68% overall, 79% for current health conditions, and 58% for scenarios involving dementia.[115] Plugging these figures into the equation as *s*, making an additional assumption about *z*,[116] and graphing the relationship between



x and *y* generates the following figure.[117] Testing would reduce errors in the region above the line, but would increase errors below it.

The figure is useful in evaluating the proposition that every patient should be tested for capacity. I am aware of no study measuring the validity of standardized capacity assessment tools in predicting judicial or quasi-judicial determinations after hearings. Whether or not such

[115]Shalowitz et al., *supra* note 57, at 493, 495.

[116]I assume that *z* is equal to 1-*x*. This is equivalent to assuming that sensitivity (1 - false negative rate) equals specificity (1 - false positive rate), which is not necessarily true. The effect of relaxing this assumption will be explored below, *infra* note 121.

[117]With known values for *s* and *z* reduced to a function of *x*, only *x* and *y* remain in the equation, so creating the graph is simply a matter of inserting values between 0 and 1 for *x* and solving for *y*, once for each value of *s*.

determinations are truly more accurate in gauging capacity, these rulings are given the force of law and thus become the "gold standard" by convention. In the absence of such direct validity measures, one might suppose that reliability estimates—how often the judgments of two independent testers agree—are in the same ballpark as validity. A very recent reliability estimate for judgments based on the MacCAT-T was approximately 0.88.[118] At this high level of test accuracy and the highest of the three surrogate accuracy levels, the base rate of incapacity would need to be 9% or higher to justify across-the-board capacity testing. In fact, the levels of incapacity observed among control groups range from 0% to 18%,[119] and are generally less than 9%. Thus, even if testing were costless and one makes assumptions that favor testing, it would probably not make sense to test every patient.

Should we test subsets of patients selected by treatment, status, diagnosis, symptom, decision, or screening? Given the same pro-testing assumptions, the answer is yes whenever the base rate of incapacity is 9% or greater. However, a great deal turns on the assumptions. Suppose capacity test accuracy were 0.78 or 0.68 instead of 0.88 or that surrogate accuracy were at one of the lower two levels. Reliability numbers in fact go as low as 0.76[120] and the 68% surrogate accuracy figure is based on the largest sample. Using these values instead would put the base rate incapacity cut-off at 36%. Perhaps it is not unreasonable to suppose that the cut-off for testing (at least for non-

[118]Vanessa Raymont et al., *The Inter-Rater Reliability of Mental Capacity Assessments*, 30 INT'L J.L. & PSYCHIATRY112, 114 (2007). This paper reports kappa (k = 0.76), not percentage agreement. I estimated percentage agreement using the formula for kappa. *See* http://en.wikipedia.org/wiki/Cohen's_kappa.

[119]Dilip V. Jeste et al., *Magnitude of Impairment in Decisional Capacity in People With Schizophrenia Compared to Normal Subjects: An Overview*, 32 SCHIZOPHRENIA BULL. 121, 126 (2005).

[120]Marson et al., *supra* note 106, at 911.

dementia patients) should be somewhere between 9% and 36%.[121] Having laid the ground-work for deciding when to assess capacity, I will now consider the various criteria one might use as triggers for testing.

2. Treatment

Existing data provide some support for Illinois's requirement of capacity testing before administering ECT. One study found 26% of ECT patients as incompetent or probably incompetent to consent to ECT.[122] The data more strongly support testing before voluntary admission. In one study, "half of the newly [voluntarily] admitted patients did not think they needed hospitalization for treatment."[123] In another, only one patient out of 40 was able to recall in a subsequent interview any part of the voluntary admission form he or she had signed.[124] Half of the interviews took place as early as between one and three days after admission.[125] A third study found that 30% of voluntarily admitted patients lacked capacity to consent to admission.[126]

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[121]As explained above, this range assumes that sensitivity equals specificity. Taking a sensitivity rate in the mid-range of reliability estimates, 0.83, and the middle surrogate accuracy figure, 68%, we can estimate the effect of allowing specificity to vary. At a 10% false positive rate, the base rate incapacity threshold for testing is 18%. At 17% (1 - *x*), the threshold is 27%. And at 24%, the cut-off is 34%.

[122]Loren H. Roth et al., *Competency to Decide About Treatment or Research: An Overview of Some Empirical Data*, 5 INT'L J. L. PSYCHIATRY 29, 40 (1982).

[123]Paul S. Appelbaum et al., *Empirical Assessment of Competency to Consent to Psychiatric Hospitalization*, 138 AM. J. PSYCHIATRY 1170, 1174 (1981).

[124]Albert B. Palmer & Julian Wohl, *Voluntary-Admission Forms: Does the Patient Know What He's Signing?*, 23 HOSP. & COMMUNITY PSYCHIATRY 250, 252 (1972).

[125]*Id.* at 251.

[126]Michael A. Norko et al., *A Clinical Study of Competency to Consent to Voluntary Psychiatric Hospitalization*, 11 AM. J. FORENSIC PSYCHIATRY 3, 11 (1990).

A fourth study found that 44% of voluntarily admitted patients were incompetent to consent to treatment, which apparently meant consent to treatment within the hospital not consent to the hospitalization itself. B.F. Hoffman & J. Srinivasan, *A Study of Competence to Consent to*

The case for across-the-board testing before administering psychotropic medication is less compelling. Among newly admitted psychiatric inpatients, the base rate of incapacity to consent to antipsychotic medication (46%) appears to be well above the threshold that would justify across-the-board testing.[127] The same is true for elderly hospital inpatients (50% incapacity).[128] It is doubtful that such high rates of incapacity exist among outpatients. The relatively low rates reported below for psychiatric outpatients are suggestive. Second generation anti-psychotic medications are prescribed not only to address acute psychosis, but also to maintain relatively normal functioning among schizophrenic and bipolar individuals. Furthermore, psychotropic medication under Illinois statute includes not only antipsychotics but also antidepressants. Many millions of Americans take antidepressants,[129] and data suggest that very few depressed outpatients lack decision-making capacity.[130]

3. Status

Treatment in a Psychiatric Hospital, 37 CAN. J. PSYCHIATRY 179, 181 (1992).

[127]*See* James C. Beck, *Determining Competency to Assent to Neuroleptic Drug Treatment*, 39 HOSP. & COMMUNITY PSYCHIATRY 1106 (1988) (in a sample of 56 hospital patients admitted consecutively to psychiatric unit, all agreed to take antipsychotic medication but 46% remained incompetent to consent throughout the 48-hour period from the initial interview, even after receiving a prepared explanation).

[128]*See* Bennett S. Gurian, *Informed Consent for Neuroleptics with Elderly Patients in Two Settings*, 38 J. AM. GERIATRICS SOC'Y 37, 39 (1990) (50% of patients taking neuroleptics in hospital had "neither insight into their disorder nor the capacity to fully comprehend the risks and benefits of medication").

[129]Nat'l Center for Health Statistics, "Almost Half of Americans Use at Least One Prescription Drug Annual Report on Nation's Health Shows,"at http://www.cdc.gov/nchs/pressroom/04news/hus04.htm (visited Sept. 17, 2007) ("Adult use of antidepressants almost tripled between 1988-1994 and 1999-2000. Ten percent of women 18 and older and 4 percent of men now take antidepressants.").

[130]*See* Edward D. Sturman, *The Capacity to Consent to Treatment and Research: A Review of Standardized Assessment Tools*, 25 CLIN. PSYCH. REV. 954, 970 (2005) (summarizing study finding

This discussion of psychotropic medication suggests that it may be important to distinguish among settings: hospital, ICU, nursing home, or outpatient, for example. Among schizophrenics, the incapacity rate varies from as high as 52% for inpatients[131] to 10% for outpatients.[132] Hospitalized elderly with medical problems have lower capacity (28% incapacity) than comparable individuals in the community (4% incapacity).[133] Nursing home residents do very poorly on capacity tests.[134] One study "reported that the majority of nursing home residents had intermediate to profound impairments in capacity."[135] Another study found that 34% to 38% of newly admitted ICU patients lacked capacity.[136] A review summarized decisional impairment among ICU patients ranging from 44% to 69%.[137]

4. Diagnosis

The two diagnostic groups most widely tested for capacity are individuals with schizophrenia

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no incapacity among outpatients with depression and 24%-25% incapacity among inpatients).

[131]Grisso & Appelbaum, *supra* note 7, at 171.

[132]J.G. Wong et al., *The Capacity of People with a 'Mental Disability' to Make a Health Care Decision*, 30 PSYCHOLOGICAL MED. 295, 302 tbl.2 (2000). This 10% figure was not significantly higher than the 0% rate observed in a control group. *Id.* at 295.

[133]L. Jaime Fitten & Martha S. Waite, *Impact of Medical Hospitalization on Treatment Decision-Making Capacity in the Elderly*, 150 ARCH. INTERN. MED. 1717, 1719 tbl. 2 (1990) (finding 28% incapacity among age 60+ inpatients with acute but not critical illness and 4% among control group).

[134]L. Jaime Fitten et al., *Assessing Treatment Decision-Making Capacity in Elderly Nursing Home Residents*, 38 J. AM. GERIATRICS SOC'Y 1097, 1097 (1990) ("Of 51 Veterans Affairs nursing home residents . . . , only 33.3% demonstrated intact decision-making capacity . . . .").

[135]Sturman, *supra* note 130, at 968.

[136]Lewis M. Cohen et al., *Do Clinical and Formal Assessments of the Capacity of Patients in the intensive Care Unit to Make Decisions Agree?*, 153 ARCH. INTERN. MED. 2481, 2483 (1993).

[137]Scott Y.H. Kim et al., *Current State of Research on Decision-Making Competence of Cognitively Impaired Elderly Persons*, 10 AM. J. GERIATRIC PSYCHIATRY 151, 159 (2002).

and dementia. As noted above, estimated incapacity rates among schizophrenics range from 52% for inpatients to 10% for outpatients.[138] Rates of incapacity among patients with dementia is quite high, with severity of illness playing an important role. One study employing several standardized instruments found 9%-23% of adults with mild dementia to be impaired in understanding.[139] Another study reported that on the most demanding legal standing (understanding choice), 93% of those with mild Alzheimer's disease (AD) (MMSE>19) and 100% of those with moderate AD (10<=MMSE<20) were incompetent.[140] A low-risk research study applying a very low threshold of capacity excluded 75% of severely demented subjects.[141] One reviewer concluded that "persons with MMSE scores in the mild to early moderate stage of dementia (MMSE 19 to 23) warrant a detailed assessment of their decision-making abilities."[142]

5. Symptom

Symptoms may be more important than diagnosis. Among individuals suffering from acute psychosis, diagnosis—schizophrenia, schizoaffective disorder or bipolar mood disorder—has been found not to correlate with capacity: "[T]he presence of cognitively related symptoms [e.g., delusions, grandiosity, and unusual thought], such as thought disorder rather than diagnosis, may

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[138]*See supra* notes 131, 132.

[139]Jennifer Moye et al., *Empirical Advances in the Assessment of Capacity to Consent to Medical Treatment: Clinical Implications and Research Needs*, 26 CLIN. PSYCH. REV. 1054, 1062 (2006).

[140]Daniel C. Marson et al., *Assessing the Competency of Patients With Alzheimer's Disease Under Different Legal Standards: A Prototype Instrument*, 52 ARCH. NEUROL. 949, __ tbl.3 (1995).

[141]B. Geiselmann, *Demented Subjects' Competence to Consent to Participate in Field Studies: The Berlin Ageing Study*, 13 MED. & L. 177, 182 (1994).

[142]J.H.T. Karlawish et al., *The Ability of Persons With Alzheimer Disease (AD) to Make a Decision About Taking an AD Treatment*, 64 NEUROLOGY 1514, 1518 (2005).

better identify the subgroup of patients who require particular support with consent procedures."[143]

Other symptoms that have been shown to be negatively correlated with capacity include:

- lack of judgment and insight, difficulty in abstract thinking, conceptual disorganization, and cognitive deficits;[144]
- cognitive dysfunction, avolition, apathy, anhedonia, inappropriate affect, and hallucinations.[145]

One study concludes that: "A more effective approach [to assessing capacity among psychiatric patients] than focusing on diagnosis is to be attentive to cognitive deficits and negative symptoms. Use of brief screening questionnaires may also be an efficient means of identifying who would benefit from more extensive capacity evaluations and/or enhanced consent procedures."[146] Screening is discussed below.

Delirium is another symptom that would appear to justify capacity testing. In one earlier mentioned study of older inpatients with delirium, researchers found a "relatively high baseline rate of functional impairment (76%) . . . and notable cognitive impairment (mean MMSE of 20.1)."[147]

6. Decision

As noted above in the sliding scale discussion, it has been observed that "patients who refuse

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[143]V. Howe et al., *Competence to Give Informed Consent in Acute Psychosis Is Associated with Symptoms rather than Diagnosis*, 77 SCHIZOPHRENIA RESEARCH 211, 214 (2005).

[144]J.G. Wong et al., *Decision-making Capacity of Inpatients with Schizophrenia in Hong Kong*, 193 J. NERVOUS MENTAL DISORDERS 316 (2005); Grisso & Appelbaum, *supra* note 7, at 169.

[145]David J. Moser et al., *Capacity to Provide Informed Consent for Participation in Schizophrenia and HIV Research*, 159 AM. J. PSYCHIATRY 1201, 1204-06 (2002); Grisso & Appelbaum, *supra* note 7, at 173.

[146]Barton W. Palmer & Dilip V. Jeste, *Relationship of Individual Cognitive Abilities to Specific Components of Decisional Capacity Among Middle-Aged and Older Patients With Schizophrenia*, 32 SCHIZOPHRENIA BULL. 98, 105 (2005).

[147]Auerswald, *supra* note 9, at 413.

treatment tend to have less capacity than those who accept it."[148] Depending on the levels of incapacity observed among refusers and acceptors, this difference might justify capacity testing of treatment refusers only. More data are needed. Note that such an asymmetric sliding screen could be justified by straightforward application of the general formula set forth above, without any balancing between autonomy and beneficence or any thumb on the treatment side of the scale.

7. Screening

The costs of capacity testing could be reduced substantially with reasonably accurate screening mechanisms. One recent study is instructive.[149] The study assessed the capacity to consent to participate in a research project of almost even numbers of subjects with schizophrenia, mild to moderate AD, and diabetes. Both the MacCAT-CR (the research version of the MacCAT-T) and a 3-item questionnaire were administered to all 101 subjects. The three questions were: "(1) 'What is the purpose of the study?' (2) 'What are the risks?' and (3) 'What are the benefits?'"[150] (These questions could easily be transposed to the treatment context.) "All 13 of the patients impaired on the MacCAT-CR understanding subscale had 3-item questionnaire total scores of 2.5 or less, and specificity (1 - false positives) at this cut score was 77.3%."[151] In other words, 36% of those who failed the 3-item test were deemed incapacitated. Note that this base rate justifies capacity testing even given relatively anti-testing assumptions. Screening tests have the potential to

[148]Francine Cournos, *Do Psychiatric Patients Need Greater Protection Than Medical Patients When They Consent to Treatment?*, 64 PSYCHIATRIC QUART. 319, 327 (1993).

[149]Barton W. Palmer et al., *Assessment of Capacity to Consent to Research Among Older Persons with Schizophrenia, Alzheimer Disease, or Diabetes Mellitus*, 62 ARCH. GEN. PSYCHIATRY 726 (2005).

[150]*Id.* at 728.

[151]*Id.* at 731.

identify with little cost a sub-set of individuals from a relatively low-risk population (13% in the study) who are at a high enough risk of incapacity (36%) to justify thorough testing.[152] In other words, a 13% incapacity base rate could be taken as the threshold for mandatory screening.

8. Implications

Even on assumptions that disfavor testing, the goal of minimizing deviations from true treatment preferences would justify full capacity testing in groups with base rate incapacity at or above 36% and capacity screening in groups with base rates at or above 13%. With the exceptions of normal control groups, outpatient schizophrenics, outpatients on anti-depressants, and perhaps the mildly demented, testing or screening would seem justified for most of the groups (by treatment, diagnosis, symptom, etc.) discussed above. One could simply mandate capacity testing or screening before treatment for anyone in one of these groups. There are several reasons, however, to pause before doing so.

First, testing and screening take time. The 3-item questionnaire described above would seem relatively quick, but to be meaningful it will be followed by full capacity testing in the third or more of subjects who fail. As many as two-thirds of those tested, or one quarter of the total screened, will have capacity. To be sure, the screening questionnaire could eliminate the need for testing in as many as two-thirds of the population, but the costs of follow-up testing would still be substantial. The opportunity costs of doctor and patient time are difficult to estimate and perhaps infeasible to trade off against erroneous treatment decisions. Quite substantial costs of screening and testing would be justified in order to bring treatment decisions more in line with patients' true preferences.

[152]Note that this threshold for screening is substantially below the level suggested by some commentators. *See* Elyn R. Saks & Dilip V. Jeste, *Capacity to Consent to or Refuse Treatment and/or Research: Theoretical Considerations*, 24 BEHAV. SCI. L. 411, 426 (2006) ("even if only *most* mentally ill people were incompetent, it might make sense at lease to inquire—do some kind of screening—of people with serious mental illness") (emphasis added).

Treatment without *bona fide* consent is illegitimate and should be avoided even at high cost.

Second, different treatment decisions require different levels of capacity. A moderately demented man may understand the situation well enough to consent to take aspirin for a headache, but be completely stymied by a more complicated intervention. The numbers reported above are specific to particular treatment decisions, and these decisions may not be typical or representative of those faced by actual patients. This problem may be mitigated to some extent where multiple studies addressing different treatment decisions reveal comparable estimates of base rate incapacity. And while screening and testing for simple decisions may not be error-rate justified in every case, at least it will take less time than for more complex decisions.

Third, differential capacity assessment by diagnosis is arguably discriminatory. However, the existence of data that show the discriminatory practice advances the goal of bringing treatment into line with true patient preferences should overcome due process, equal protection, and ADA challenges.[153] The disparate impact of the practice would seem similarly justifiable.[154]

9. Proposal

I recommend that documented capacity screening and, if warranted by screening, full testing be required before medical treatment whenever there is good reason to believe that the patient may lack capacity to consent to treatment.[155] The proposed statute would provide a non-exhaustive list of

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[153]The ADA prohibits: "Providing . . . different . . . services to people with disabilities, *unless* . . . different services are necessary to provide qualified individuals . . . services that are as effective as those provided to others." ROBERT M. LEVY & LEONARD S. RUBENSTEIN, THE RIGHTS OF PEOPLE WITH MENTAL DISABILITIES 167 (1996) (emphasis added).

[154]RALPH REISNER ET AL., LAW AND THE MENTAL HEALTH SYSTEM 1132 (3d ed. 1999) (ADA prohibits disparate impact).

[155]Others have made similar recommendations. *See* Edwards Etchells et al., *Bioethics for Clinicians: 3. Capacity*, 155 CAN. MED. ASS'N J. 657, 658 (1996) ("If it is unreasonable to presume capacity, then a capacity assessment should be undertaken.").

"good reasons" based on existing data.[156] On the list would be: (1) the patient is seeking voluntary admission to a psychiatric unit or facility;[157] (2) the patient is in an inpatient facility and the treatment is psychotropic medication;[158] (3) the treatment is ECT; (4) the patient is in the ICU; (5) the patient is in a nursing home; (6) the patient is suffering from acute psychosis, cognitive deficits, negative symptoms (listed above), or delirium;[159] and (7) the patient has an MMSE score less than 24. Note that to minimize discrimination I omit any reference to diagnosis. In any tort or civil rights action based on unauthorized treatment, no treating physician, other health professional, or facility could rely on the presumption of capacity if the physician, professional, or any employee of the facility knew or should have known there was good reason to believe that the patient may have lacked capacity to consent to treatment and the physician, professional, or employee did not screen or test for capacity.

This last provision should hopefully go some distance in solving the problem that mandatory capacity assessment statutes are basically ignored. Other more direct enforcement mechanisms are possible. The failure to screen or test where required could give rise to a private cause of action for

[156]Better data could support a statute or practice guidelines that would simultaneously account for different variables. Such statistical prediction models have proven very useful in other contexts. *See generally* IAN AYRES, SUPER CRUNCHERS: WHY THINKING-BY-NUMBERS IS THE NEW WAY TO BE SMART (2007).

[157]I am not the first to make the recommendation. *See* Francine Cournos et al., *Report of the Task Force on Consent to Voluntary Hospitalization*, 21 BULL. AM. ACAD. PSYCHIATRY L. 293, 299 (1993). The task force, however, would have set a much lower capacity threshold.

[158]One researcher has gone further in this context, proposing that there should be a presumption of *in*competence. Gurian, *supra* note 128, at 43.

[159]Here, the supporting evidence is correlational within diagnosis rather than measuring absolute levels by symptom across diagnoses. Additional data are needed. *See* Laura B. Dunn, *Capacity to Consent to Research in Schizophrenia: The Expanding Evidence Base*, 24 BEHAV. SCI. L. 431, 434 (2006).

a set statutory amount. However, the amount reasonably at issue seems unlikely to justify many lawsuits. Administrative procedures may make more sense. The state health authority (or Joint Commission on hospital accreditation) could perform periodic unannounced inspections of medical records and fine health care providers for failing to document capacity testing where required.[160] As others have suggested for informed consent generally, funds raised through fines could be used to compensate individuals who were harmed by failures to assess capacity.[161]

10. Counter-Arguments and Responses

Bruce Winick has argued that capacity testing should not be required before an individual voluntarily admits himself to a mental hospital.[162] Winick provides five arguments, which could apply to mandatory capacity screening and testing outside the voluntary admission context: (1) "requiring such an inquiry for all mental patients seeking hospital admission . . . seems to accept the 19th-century assumption that mental illness per se destroys decision-making capacity";[163] (2) once one starts questioning capacity, there is no logical stopping point and this "would necessitate an inquiry into the issue of competence every time an individual with mental illness seeks to exercise a

[160]Failures to attempt to consult with surrogates where capacity is lacking should be penalized in the same way. *See* C. Dennis Barton, Jr. et al., *Clinicians' Judgment of Capacity of Nursing Home Patients to Give Informed Consent*, 47 PSYCHIATRIC SERVICES 956, 956 (1996) ("None of 15 subjects whom clinical staff identified as clinically incompetent was provided with surrogate decision makers in accordance with procedures outlined in state law.").

[161]1 PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE & BIOMEDICAL & BEHAVIORAL RESEARCH, MAKING HEALTH CARE DECISIONS: THE ETHICAL AND LEGAL IMPLICATIONS TO THE PATIENT-PRACTITIONER RELATIONSHIP 152 n.3 (1982) (quoting Leonard L. Riskin, *Informed Consent: Looking for the Action*, 1975 U. ILL. L.F. 580, 606-07).

[162]Bruce J. Winick, *The MacArthur Treatment Competence Study: Legal and Therapeutic Implications*, 2 PSYCH. PUB. POL. & L. 137 (1996) (hereinafter Winick, *MacArthur*).

[163]*Id.* at 154.

right";[164] (3) incompetency labeling "imposes serious adverse social consequences and psychological damage";[165] (4) because competency is often a close question, the presumption of competence prevents "excessive paternalism";[166] and, finally, (5) better adherence to the presumption of competence will "produce competency adjudications that are considerably more accurate and more protective of individual autonomy than under present practices."[167] None of these arguments has merit.

First, as demonstrated above, combining certain plausible assumptions with actual incapacity data shows that across-the-board screening and testing of individuals seeking voluntary admission can be expected to reduce instances in which decisions deviate from the individuals' true preferences. That all such individuals lack capacity was not one of the premises for this showing. Rather, the showing was based on several estimates of actual incapacity. But one need not look at the numbers to see the flaw in Winick's position—indeed, he concedes it by using the wiggle words "seems to accept." There would be no need for any inquiry into decision-making capacity if one truly accepted the 19th-century assumption that the mentally ill uniformly lack capacity. Requiring an inquiry assumes just the opposite: that some mentally ill individuals have capacity.

The second argument, a parade of horribles, is also a non-starter.[168] Requiring capacity

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[164]*Id.*

[165]*Id.* (citing, inter alia, Bruce J. Winick, *The Side Effects of Incompetency Labeling and the Implications for Mental Health Law*, 1 PSYCH. PUB. POL'Y & L. 6 (1995) (hereinafter Winick, *Side Effects*)).

[166]Winick, *MacArthur*, *supra* note 162, at 156-57.

[167]*Id.* at 158.

[168]That has not stopped others from ascribing to it. Francine Cournos et al., *Report of the Task Force on Consent to Voluntary Hospitalization*, 21 BULL. AM. ACAD. PSYCHIATRY L. 293, 297 (1993).

testing before medical treatment says nothing about other contexts. Indeed, there are very good reasons to treat medical care differently. Medical care without competent consent is battery, which carries civil and perhaps criminal sanctions. Entering into a contract or making a will without capacity may raise other issues, but certainly does not constitute a tort or crime as serious as battery. Doctors are trained to test capacity, or at least to understand the basics of informed consent, and are available testers every time medical care takes place. No comparable expert is already on the scene in other contexts.

Third, Winick is no doubt correct that being labeled incompetent has adverse consequences. But foregoing capacity testing on this ground is a bit like taking your malfunctioning car to a mechanic and, for fear of bad news, telling her not to look under the hood. Being labeled incompetent is bad; being incompetent is worse. To be incompetent is to lose control over the most basic aspects of your life. Adding a label does not change that.[169] Relatives do better than doctors in figuring out what incapacitated patients would want. In order to shift decision-making responsibility, however, there must be a determination that the patient lacks capacity and that determination may carry negative consequences. Using the narrower term "incapacitated" rather than the more pejorative "incompetent" may go some distance toward reducing stigma,[170] but ultimately the question is whether patients would prefer more accurate decision making by family even though the cost may be an incapacity label.

The benefits of more accurate decisions by family outweigh the harms of incapacity labeling. One of Winick's objections to incompetency labeling is that "surrogate decision makers will likely

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[169] *Cf.* Winick, *Side Effects*, *supra* note 165, at 13 ("Application of an incompetency label usually produces an actual and obvious loss of control.").

[170] *Id.* at 40.

be impersonal state officials or employees whose paternalism is not based on love and is rarely nurturing."[171] Not so when, as under my proposal, the surrogate is a patient-appointed proxy, court-appointed guardian, or, more likely, statutorily-appointed close relative. Indeed, it is the status quo—unconstrained decision making by the treating physician—that will often place a stranger at the wheel.[172]

Winick's fourth and fifth arguments are directed toward the presumption of competence, not testing per se, but they could be read broadly as attacks on mandatory testing. On the fourth point, I am not sure competency is so "often a close question." The high observed inter-rater reliability of standardized capacity assessment instruments suggests that judgment calls are rather infrequent. In any event, a mandatory testing regime can leave room for the presumption of capacity in close cases. I propose that the presumption be suspended only when no screening or testing took place. Ultimately, whether "paternalism" is "excessive" or whether a tie-breaker presumption of capacity increases or reduces accuracy depends on where one sets the capacity bar. Apart from discussion of the sliding scale, this article does not address that question. Winick's final argument is that presuming competency protects individual autonomy. As long as the capacity bar is set at the right level, the presumption protects only the illusion of autonomy by ascribing capacity to some who lack it. A truly incapacitated patient has no genuine autonomy. That such a patient agrees to treatment is a happy accident, not an expression of will.

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[171] *Id.* at 14; *see also id.* at 30 ("[P]aternalism on the basis of parental love and a knowledge of the child's interest rooted in actual familiarity is much more likely to be beneficial than that engaged in by impersonal state actors who lack an ongoing relationship with the individual.").

[172] Winick also observes that the negative consequences of incompetency labeling are increased when there is a formal hearing and "official finding of incompetency by a judicial or administrative decision maker." *Id.* at 28. Thus, a clinical finding by a health care professional, as contemplated here, has fewer negative effects.

D. Application and Implementation of Model

Recall again the three hypotheticals set forth at the outset: (1) a married woman with delirium; (2) a widow with dementia and evening delusions; and (3) an unmarried bipolar man in a manic state. In light of the patients' symptoms and the proposed treatment, the first step in each case, assuming no emergency, would be capacity screening, followed by full testing if indicated. Any patient who had capacity should of course be allowed to make his or her own treatment decision. If any patient lacks capacity, the next step would be to look for an advance directive, health care proxy, or court-appointed guardian. Assuming none exists, the health care decision would be made by a statutory surrogate, if available: the husband in the first hypothetical, the only adult child in the second hypothetical, and, most likely, the man's parents in the third hypothetical. A patient could insist on a second opinion regarding capacity if the surrogate refuses treatment. The surrogate's decision for treatment or non-treatment otherwise would be final unless the doctor obtains a court order overruling the decision as clearly inconsistent with the patient's expressed preferences or best interests. If the parents in the third hypothetical consented to voluntary admission, the bipolar man would have a right to a second opinion within 24 hours of such a request.

To make the proposal concrete in one state, Illinois would need to enact the following changes. A new section to the Act should mandate capacity screening and testing where there is good reason to doubt capacity, including an exemplary list of good reasons. The Act should also state that screening and testing is to be done by standardized instrument wherever feasible and expressly prohibit application of the asymmetric sliding scale. The Act should be amended to state that an incapacitated patient's assent to treatment when the surrogate is refusing treatment does not qualify as an "objection" so as to nullify applicability of the Act, but that the patient can request a second opinion as to capacity. A section providing for judicial override of surrogate decisions on

the treating physician's petition should be added to the Act. The mental health exceptions to the Act and related limitations in the Code should be repealed insofar as they include instances of patient assent. A 24-hour second opinion option should be added to the voluntary admission section of the Code.

IV. EXTENSIONS

A. When There Is No Surrogate

This article has assumed that a statutory surrogate will be available to make decisions when the patient is incapacitated. Of course, this assumption will sometimes be false. A patient may have no willing or available surrogate. One solution in such a case is to revert to effectively unconstrained physician decision making. That solution has been suggested by at least one commentator.[173] The justification to prefer surrogate decision making set forth in this article is surrogates' greater accuracy than doctors in predicting patient preferences. When there is no surrogate, there is no readily available decision maker with proven increased accuracy. The treating physician is at least available.

There are, however, other reasons to resist unrestrained physician control. Medical treatment without meaningful consent is battery.[174] It is not meaningful for a doctor to "consent" to her own treatment decisions. Where else can we turn for consent? The existing statutory fall-back option is guardianship. But guardianship is a time-consuming process, and it may be infeasible to appoint a

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[173]*See* Francine Cournos, *Do Psychiatric Patients Need Greater Protection Than Medical Patients When They Consent to Treatment?*, 64 PSYCHIATRIC QUART. 319, 326 (1993) ("When a patient accepts treatment, the agreement of the treating physician, and, *when available*, the family, constitutes a check on the reasonableness of the patient's decision.") (emphasis added).

[174]Some states have carved out exceptions. *See* Grant H. Morris, *Judging Judgment: Assessing the Competence of Mental Patients to Refuse Treatment*, 32 SAN DIEGO L. REV. 343, 380 (1995) (Under California statute, "[n]onprotesting [involuntarily committed mental] patients may be treated with psychotropic medication without giving a competent consent.").

guardian before treating every incapacitated patient, especially when the patient is assenting to treatment. This problem is exacerbated in the outpatient setting, where much treatment of dementia takes place. It may make sense to create a more expedited process to obtain interim consent while the guardianship process is pursued. An ethics review board or, probably better, independent patient advocate could be made available for consultation and provisional decision making.

B. When the Patient Refuses Treatment

Approximately 10% of psychiatric patients refuse treatment.[175] When the patient is incapacitated, there is some surface appeal in treating assent and refusal the same. What does it matter what the patient says if the patient lacks capacity? The implication of accepting this position, in light of this article's thesis with respect to assent, would be to shift decision making authority to a surrogate. The surrogate would have authority to overrule treatment refusal in the same way the surrogate would have authority to overrule treatment assent. That position should be rejected. Treatment assent and refusal are not parallel in important respects.

Patients have a general right to refuse treatment,[176] but have a right to treatment only in limited circumstances (*e.g.*, when the state is custodian).[177] Overruling treatment refusal more directly implicates privacy and due process interests and therefore requires a more formal

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[175]Paul S. Appelbaum, *The Right to Refuse Treatment With Antipsychotic Medications: Retrospect and Prospect*, 145 AM. J. PSYCHIATRY 413, 418 (1988).

[176]*See* Rebecca J. O'Neill, *Surrogate Health Care Decisions for Adults in Illinois - Answers to the Legal Questions That Health Care Providers Face on a Daily Basis*, 29 LOY. U. CHI. L.J. 411, 460-61 (1998) ("As the Illinois Appellate Court stated, '[t]he right to refuse medical treatment has been recognized under constitutional right-to-privacy principles and is deeply ingrained in common law principles of individual autonomy, self-determination, and informed consent.'") (citing *Ficke v. Evangelical Health Sys.*, 674 N.E.2d 888, 889 (Ill. App. Ct. 1st Dist. 1996)); 410 ILCS 50/3(a); 755 ILCS 40/5.

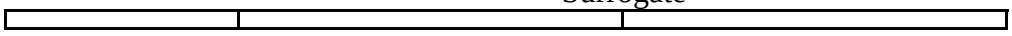
[177]MICHAEL L. PERLIN, LAW AND MENTAL DISABILITY 169-213, §§ 2.02-2.07 (1994).

adjudication of capacity and appropriateness of treatment. Overriding a refusal also requires deception, coercion, or force. It makes sense to more carefully constrain exercise of such disfavored methods.[178] And, finally, treatment over refusal is often less effective than treatment with assent.[179] One might expect doctors and surrogates to appreciate and factor in this last point, but the other two distinct aspects of overriding refusal—patient rights and coercive methods—require special protection.

One alternative would be to combine the second opinion and independent patient advocate proposals outlined at different points above. Specifically, physicians and surrogates seeking to override patient refusal would need to obtain a second medical opinion finding both incapacity and treatment appropriateness, as well as consent from an independent patient advocate who would discuss the issues with physician, surrogate, and, to the extent possible, patient. Repeating capacity testing can substantially increase confidence in an incapacity finding,[180] and the additional pro-treatment assessments by a second medical professional and a patient advocate would provide some assurance that treatment is appropriate. As with patient assent, surrogates would have the power, subject to court overrule, to veto treatment. The following 2 x 2 box summarizes the tentative proposal:

Box. Summary of Outcomes By Assent/Consent to Treatment

Surrogate



[178]On the clinical costs of coercion, see APPELBAUM & GUTHEIL, *supra* note 81, at 204.

[179]Bruce J. Winick, *Competency to Voluntary Hospitalization: A Therapeutic Jurisprudence Analysis of* Zinermon v. Burch, 14 INT'L J. L. & PSYCHIATRY 169, 198, 213 (1991).

[180]At 76% test accuracy with a 24% false positive rate and 36% incapacity base rate, a single positive incapacity test is 64% likely to show true incapacity. Testing twice increases confidence to 85%.

Patient	Yes (Consent)	No (Refusal)
Yes (Assent)	Treatment	No treatment, subject to second opinion at request of patient or judicial override at request of doctor
No (Refusal)	Treatment, if second opinion confirms incapacity and treatment appropriateness and independent patient advocate consents	No treatment, subject to judicial override at request of doctor

This proposal can be criticized as both over- and under-protective of patient rights. Requiring a second opinion would often be cumbersome in the outpatient setting. On the other hand, providing less than notice and a hearing arguably falls short of constitutional requirements. Whether the more informal process proposed here is constitutional is outside the scope of this article. It is important to note, however, that more formal process does not necessarily translate into greater protection of patient interests. Doctors will develop strategies to avoid costly and time-consuming court hearings. These strategies may include: discharging, failing to admit, or otherwise not treating refusing patients; selectively disclosing information to ensure assent; coercing "voluntary" treatment; and treating non-emergency situations as emergencies to avoid the consent requirement.[181] Less costly procedures, like repeat capacity testing, may hold more potential in promoting patient autonomy and well being.

Conclusion

An incapacitated patient cannot meaningfully consent to medical care. And yet, current legal

[181] *E.g.*, Morris, *supra* note 174, at 385-86; Delila M.J. Ledwith, Jones v. Gerhardstein: *The Involuntarily Committed Mental Patient's Right to Refuse Treatment with Psychotropic Drugs*, 1990 WIS. L. REV. 1367, 1391.

rules and the beneficence imperative of doctoring provide strong incentives to take at face value such illusory consent. Two such legal rules are the presumption of capacity and, in mental health, the requirement for court proceedings. The beneficence principle means that doctors generally place patient well being above other values, including self-determination. Together, these incentives in fact dominate actual practice. Doctors tend to question capacity only when the patient refuses treatment. If the patient assents to treatment, it is often given with no inquiry into patient capacity.This practice of respecting illusory consent superficially advances the goal of patient autonomy. "The patient said yes, so we're just respecting that decision." A more subtle version of this argument is that even an incapacitated individual has some residual autonomy, so, at least when the patient is making a good decision, we should respect that autonomy.[182] But autonomy means respecting bad decisions as well as good ones. The best way to advance the goal of self-determination is to make the treatment decisions that the patient would have made if the patient had capacity. The question should be which decision maker will best accomplish this end.

The patient, by definition, is incapacitated, so that leaves, in most cases and short of going to court, the doctor and the family. The current system in Illinois and many other states effectively assigns treatment decisions, if the patient assents, to doctors. Relatives do better than chance and better than doctors in predicting patient preferences. Because the patient's wishes should remain the gold standard even if the patient loses the ability to make decisions for himself, relatives rather than doctors should call the shots. Consulting relatives is obviously much less burdensome than going to court, but experience outside the mental health context demonstrates that reducing this cost of capacity testing may not be sufficient to induce doctors more routinely to assess capacity.

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[182]Bruce J. Winick, *Competency to Voluntary Hospitalization: A Therapeutic Jurisprudence Analysis of* Zinermon v. Burch, 14 INT'L J. L. & PSYCHIATRY 169, 192-93 (1991).

If the goal is to minimize deviations from actual patient preferences, and costs of testing are set to one side, three variables determine whether capacity testing should take place: (1) the accuracy of the test; (2) the base rate of incapacity in the population tested; and (3) the accuracy of surrogates. There are quite a lot of data on each of these three variables, which together suggest several types of patients and treatment decisions where capacity assessment should be mandatory. These mandates could be enforced through a system of administrative monitoring and penalties.

True respect for individual autonomy sometimes requires overriding what the individual says. This may be true when a patient lacks decision making capacity, even if the patient agrees to beneficial treatment. The same patient might not have agreed to treatment if the patient had had capacity. Doctors in this situation will be very unlikely to allow the goal of patient well being to be trumped by the goal of patient self-determination. Family too may be imperfect, but the data suggest they will do better at honoring a patient's true treatment preferences. The goal of self-determination sometimes requires that capacity be tested and, where incapacity is found, decisions delegated to family.