The Paradox of Consent for Capacity Assessments

Peter Koch

The use of decision-making capacity assessments (DMCA) in clinical medicine is an underdeveloped yet quickly growing practice.[1] Despite the ethical and clinical importance of these assessments as a means of protecting patient autonomy, clinicians, philosophers, and ethicists have identified a number of practical and theoretical hurdles which remain unresolved.[2] One ethically important yet largely unaddressed issue is whether, and to what extent physicians ought to inform and obtain consent from patients prior to initiating a capacity assessment. In what follows, I address the following question: Must, or should, physicians obtain consent for capacity assessments? I argue that physicians have an ethical obligation to obtain express patient consent for capacity assessments, and in doing so, I challenge the predominant view which requires physicians to merely inform patients without obtaining consent. I then identify an underlying philosophical paradox that complicates the clinician's duty to obtain consent: in short, consent is needed for an assessment of one's ability to consent. Finally, I recommend a practical solution to this paradox of consent for capacity assessments by proposing a model of double consent from both the patient and health care representative.

I. Capacity

Decision-making capacity (DMC) in the context of healthcare is an individual's cognitive and behavioral ability to make and communicate medical decisions. (Henceforth the term *capacity* refers to a patient's ability to make medical decisions as assessed by physicians or other medical professionals within a medical context, and is taken to be distinct from *competency*, which often refers to a legal determination.)[3] DMC is an essential component of the professional, legal, and ethical principle requiring physicians to obtain informed consent prior to providing medical care to patients. The centrality of DMC in the process of informed consent is reflected in the American Medical Association guidelines on informed consent, which recommend that a physician initiates the informed consent process by assessing a patient's ability to understand information and make relevant decisions.[4] If the patient is determined to have DMC, the physician then presents relevant information to the patient, including the patient's diagnosis, the nature and purpose of the potential treatment options, and the associated risks and benefits of each option. Taken together these steps constitute the process of informed consent. Therefore, in order for a patient to provide their informed consent or refusal, a qualified assessor must recognize the individual as bearing the capacity to appreciate relevant information and then communicate their consent or refusal.

DMC is typically described as being comprised of five other sub-capacities, which reflect the informational and behavioral components of informed consent: the abilities to understand relevant information, appreciate the significance of a particular decision, reason through a decision-making process, express a choice, and consistently identify with basic values.[5] At times, these categories are extended to further include, for example, that person's emotive abilities.[6] DMC is function-dependent or decision-relative, mean-

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ing that a person may have the capacity to make one decision but not another, and so they are capable of providing consent or refusal to some elements of care but not others. Whether or not a patient has DMC for a particular decision depends upon the nature of the care associated with that decision as well as that individual's ability to understand the related information and outcomes. For example, a patient may have the capacity to decide whether to receive a treatment orally or topically but may lack the capacity to decide whether to amputate a gangrenous limb.

Because of the multidimensional nature of DMC as both a function of cognitive and behavioral capacities, it is often the case that physicians are uncertain about whether a patient has DMC. Some patients may have the cognitive abilities to make decisions, but are limited in their ability to communicate their decisions, while others may provide strong behavioral evidence of DMC, but over time this evidence weakens. Examples of such patients include those with various stages of dementia, ambivalent patients, patients with cognitive disabilities or who suffer from psychiatric disorders, or, in some cases, simply quirky patients. When presented with these patients, physicians will often perform an assessment of the patient's capacity, first through an informal though targeted conversation, and then, if the concern remains, through the use of standardized DMC assessment tools.

Since the patient's liberty and bodily integrity are at risk with a capacity assessment, ought physicians obtain patient consent for a capacity assessment? More specifically, ought physicians obtain a patient's explicit consent for capacity assessments? This question has remained largely neglected — and surprisingly so, given the broad and enduring attention that the notions of consent and capacity have received in the related literature.

II: Decision Making Capacity Assessments (DMCA's)

While the medical profession has refrained from adopting any uniform method of assessment, clinicians — typically psychiatrists — perform DMCAs using directed clinical interviews, formal standardized assessment tools, or both.[7] Examples of these assessment tools include the Aid to Capacity Evaluation (ACE), which is used to gather information through a series of questions meant to capture the components of informed consent.[8] These different domains include the patient's understanding of her own medical condition, the proposed treatment plan, alternative treatment options, and the consequences of the patient's medical decision. Following the ACE, a clinician may ask: *What problems are you having right now? Are there other treatments that you could have? Can you refuse antibiotics? What would happen if you do not take antibiotics?* If the patient is capable of coherently and accurately answering these questions, then the clinician may infer that the patient has capacity for making certain decisions.

Besides the ACE method, there are many other evaluation tools such as the Hopkins Competency Assessment Test (HCAT), the Understanding Treatment Disclosure test (UTD), and the Ability to Consent Questionnaire (ACQ).[9] These assessments vary with respect to duration, reliability, and validity; a number of important questions have emerged regarding the efficacy of these tests and the philosophical commitments which ground them.[10] Despite the variation between these assessment tools, each model requires a targeted interaction with the patient whose capacity is in question followed by a judgment of whether the patient has capacity for the relevant medical decisions.

The results of the DMCA are used to determine the degree to which the patient will be involved in future medical decisions pertaining to their own care. What is at stake, then, is the patient's right to control what happens to their body, a fundamental liberal right that is protected by one's autonomy, bodily integrity, and liberty.[11] The protection of these rights exposes the gravity of what is at stake in these assessments: if a patient is treated as if they lack DMC when they actually have DMC, or vice versa, then these physicians risk violating the fundamental rights of the patient.

More broadly, the outcome of a DMCA — whether accurate or not — determines which basic rights and principles will guide that patient's care. If a patient is deemed to lack capacity — notably, an epistemological claim — then they will not have the opportunity to offer their informed consent or refusal to future medical care, unless and until they regain DMC. This out-

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come inverts the ethical and legal framework from one which incorporates a patient's autonomous decisions, informed by considerations of the patient's well-being (along with other professional obligations) to one centered around the patient's wellbeing, ideally informed by substituted judgment of the patient's values.

III. Consent for Capacity Assessments

Since the patient's liberty and bodily integrity are at risk with a capacity assessment, ought physicians obtain patient consent for a capacity assessment? More specifically, ought physicians obtain a patient's explicit consent for capacity assessments? This question has remained largely neglected — and surprisingly so, given the broad and enduring attention that the notions of consent and capacity have received in the related literature.[12] The questions themselves are complicated by the underlying circularity of the situation: capacity assessments are performed when it is unclear if a patient can provide consent at all. Further, raising such questions likely invites concern from physicians about introducing still more time-consuming steps in an already time-sensitive encounter with their patients. Even with these concerns in mind, I argue here that we should answer both of these questions in the affirmative, and I propose a practical solution to the circularity of the encounter. To defend this position, first consider the following scenario.

Imagine a newly developed assessment tool called the Super Capacity Assessment Glasses, which are designed to replace standard DMCA's. The Super Capacity Assessment Glasses (SCAG) are an advanced pair of eyeglasses used by the assessor which, when worn, can tell the wearer whether a person has decision making capacity. This is achieved by remotely assessing that person's brain activity. To use the SCAG, the physician asks a series of standard questions to the patient such as "How has your day been going?" and "Have you been enjoying the weather?" The SCAG then automatically captures the patient's neurological responses to these questions and generates conclusions as to whether the patient has DMC, for what duration, and for which decisions. The conclusions are visible to the assessor on the interior of the SCAG lens to the assessor. The practical outcomes of this assessment, including the risk of being excluded from future decision making, are the same as in the case of typical DMCA's. Here we can ask: Should the physician obtain informed consent from the patient to participate in the capacity assessment in which the SCAG is used?

In this scenario, it seems clear that the assessor should obtain patient consent prior to performing the SCAG assessment, given the targeted nature and the medically-related stakes of the assessment. It follows from this conclusion that if there are no relevant differences between the SCAG assessment and typical DMCA's, then DMCA's require informed consent as well. There are no evident and relevant differences between the scenarios. Both the traditional medical professional who serves as a capacity assessor and the user of the SCAG are engaged in a remote assessment of the patient's DMC; neither is performing an invasive procedure in order to formulate the assessment. Both are developing the assessment by analyzing the patient's responses, although one through verbal and physical cues and the other through remotely detected brain activity. The assessor in both cases presents as someone with a series of fairly standard questions which appear as conversational but are directed towards a further treatment-related goal. Although the SCAG user likely has a more accurate assessment based on their tool, this is a merely incidental difference; one could easily imagine a particularly keen evaluator who is capable of the same degree of accuracy in their assessment as the user of the SCAG. And so, lacking any morally relevant difference between the SCAG and a typical capacity assessment, there is no principled reason why we ought to obtain consent for the SCAG Assessment but not for a standard capacity assessment.

The SCAG thought-experiment reveals the intuition that capacity assessments require patient consent. As previously mentioned, this is an issue which is rarely addressed, and only superficially when done so; it is largely, but not completely, overlooked in the relevant literature. When the topic is addressed, one commonly referenced approach for performing DMCA's includes the requirement to *inform* the patient of the DMCA prior to performing the assessment.[13] Notably, however, this recommendation stops at the point of informing a patient and does not include the requirement of obtaining the patient's consent after the information is provided. If this requirement is taken simply as a suggestion to provide information without obtaining any consent at all, then it is surely insufficient for meeting the ethical demands of the physician-patient encounter, since it does not rule out merely informing the patient and then proceeding regardless of the patient's response to the information. For example, this would not rule out cases in which a physician informs a patient of the purpose of an assessment, and then proceeds despite the patient's *actual* (but unknown) inability to understand the information. Such an engagement would fulfill the requirement to inform the patient of the capacity assessment, but would not fulfill the purpose of informing patients in the first place, which is so that the patient can provide permission and consent to participate in the assess-

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ment based on information that they are capable of understanding. Merely informing patients, then, is in itself an insufficient model for initiating a DMCA for patients.

A more plausible way to understand this requirement is that provision of information serves as a step toward obtaining patient consent. Notably, adopting this view presumes that physicians should obtain some form of consent to capacity assessments in the first place. However, when this position has been presented, it includes the caveat that additional or express consent to the DMCA is not required, as consent is already implied:[14]

> When patients come for medical care — whether inpatient or outpatient — they or their appropriate surrogates consent at the outset to the performance of routine, non-invasive procedures that are part of that care … An assessment of decision-making capacity, if required, is similarly an intrinsic part of patient care, about which patients should be informed, but for which a discrete consent process is not required.

I challenge the notion that implied consent is sufficient, or even present, in these cases. The reason that we should reject this view is because of the structure of implied consent model. The notion of implied consent hinges upon the following: If a patient has implicitly consented to X, then that patient has already given his or her consent to a general body of care Y, to which X belongs. For example, when a patient gives consent to a general physical examination, then this implies that the patient has consented to each part of the examination, including measurements of their blood-pressure and height. The practitioner is not required to obtain express consent from the patient for each particular element of care. But the structure of implied consent includes an additional requirement: In order for a patient to provide implied consent to an element of care, the patient must *understand* that the specific element of care is implied by the general care. If a person is ignorant of the fact that general care Y implies particular procedure X, or cannot understand that Y implies X, then their consent to Y cannot imply their consent to X.[15]

Given this structure, there are at least two reasons to suspect that patients do not provide implied consent to DMCA's. First, most patients do not undergo capacity assessments as part of their general care, and so DMCA's are not routine (where routine is understood as typical) elements of medical care.[16] Therefore, it is not evident that DMCA's should be part of a patient's reasonable expectations while in the clinical setting. Given the infrequency of DMCA's compared to, for example, measurements of height and weight, the burden of proof rests on those who assume that patients understand that DMCA's are part of routine care. The second reason why we should reject the implied consent model is because the patient population that requires a DMCA is the very patient population with the highest risk to *not* understand what care is implied by general care. If a physician is concerned that a patient lacks capacity, then that physician will likely share the parallel concern that the patient does not understand the link between their consent to general care (if this is even possible) and their consent to particular assessments such as a capacity assessment.

This second reason also rules out the potential reliance on *tacit* consent, in which the patient does not express consent, but consent is inferred from the patient's behavior. Since capacity assessments are generally only invoked when a patient may lack capacity for decision making, it is unwarranted to read off of the patient's behavior for consent, since their behavior is what is triggering the capacity assessment; it is precisely the patient's capacity to consent that is in question in the encounter.[19] Thus physicians should not rely on tacit consent to fulfill the consent requirement for the administration of a DMCA.

Others might contend, however, that even if patients have not implied their consent, physicians can still presume the patient's consent. Presumed consent differs from implied consent in that presumed consent is the notion that, *if asked*, the patient would have consented to a medical procedure. Presumed consent requires the high probability that the individual would have actually consented to the particular procedure — a fact that is, in theory, empirically verifiable.[18] For example, presumed consent is often used to justify the initiation of medical treatment for those patients who suffer a severe and treatable injury yet are temporarily incapacitated, such as a person who suddenly collapses in a public square. We can presume that, if asked, this person would consent to be treated, and so responders will attempt to treat the person. However, because of the lack of attention that the matter has received, we have no data suggesting that patients would consent to capacity assessments if asked. Since there is no empirical basis upon which to presume consent, then the presumption would be, as it stands, ungrounded. Furthermore, clinicians typically invoke the notion of presumed consent when a patient definitively lacks the capacity to consent to the necessary care — for example, when found unresponsive on the side of the road. If a physician is certain that a patient lacks the ability to participate in a capacity assessment, then the capacity assessment is not necessary in the first place.

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If consent is required, yet we cannot rely on merely informing patients, implied consent, tacit consent, or presumed consent, then practitioners ought to safeguard patients' rights by obtaining express consent from patients. Express consent would require informing the patient of the purpose and potential outcomes of the DMCA, and then obtaining the patient's verbal or written consent to proceed with the DMCA. This practice is not without precedent; a parallel structure is found in mental health evaluations.[20] In a number of institutions, mental health evaluations require the express consent of the individual undergoing the evaluation or their health care representative. These evaluations are similar to capacity assessments in that they are often non-invasive yet have important implications on the ways in which the patient participates in their own care. However, the primary difference between mental health evaluations and capacity assessments is that individuals with suspected mental health challenges are not necessarily suspected of lacking DMC, while those undergoing a capacity assessment are necessarily questioned about their DMC. If express consent is often required for mental health evaluations, where DMC is not necessarily in question, then this offers further support for the conclusion that physicians ought to obtain express consent for capacity assessments, where DMC is necessarily questioned.

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There is, however, an underlying paradox which has been surfacing in myriad ways in the discussion up to this point. On the one hand, the patient's consent is needed for the capacity assessment. On the other hand, a capacity assessment is needed in order to validate the patient's consent. This leaves us with the unusual situation in which the result of the assessment is required for the initiation of the assessment: a catch-22. This paradox inherently complicates the practical viability of obtaining consent for DMCA's.

Consider a scenario in which a patient communicates permission to perform a DMCA before she is known to have DMC for such an assessment. If it turns out that the patient was capacitated when they granted permission, then they will have provided valid consent to the assessment. Only in retrospect would this be recognized as valid and so be unproblematic. If it turns out that the patient lacked capacity and had merely verbalized permission without understanding the nature of the evaluation, then they may have simply communicated affirmation or assented. In retrospect, the physician would have performed the assessment without the patient's consent, which is problematic for the reasons outlined above.[21] Given the paradox of obtaining consent for capacity assessments, how might physicians and medical professionals respond to this challenge?

A Tentative Solution: Dual Consent Model

Physicians ought to obtain express consent for performing capacity assessments, but this obligation is undermined by the paradoxical nature of the situation: physicians must obtain consent to verify if the patient *is able to* consent. There is, however, a practical resolution to the standard case of obtaining consent for capacity assessments: In cases when a patient's capacity is in question and when a formal capacity assessment is requested by the medical team, I propose that physicians or another member of the medical team adopt the precautionary measure of obtaining express consent from both the patient and their health care representative: dual consent. (Though I call the model dual consent, I recognize that in cases when the patient in fact lacked capacity, then there would only have been single consent, that from the health care representative.) For example, imagine a patient who is accompanied by their spouse — in this case,also their health care representative — to a hospital.After a short interaction, the medical team is uncertain about the patient's DMC. If the physician wishes to perform a capacity assessment, then this model would entail that the physician discusses the nature of the capacity assessment and the importance of its outcome with both the patient and their spouse together, obtaining express consent from both before administering a formal capacity assessment. This safeguards the medical team from obtaining mere assent from the patient when consent was not possible given the patient's lack of decision making capacity. Further, this measure involves the patient's health care representative in medical decision making early on in treatment, which would likely serve to improve their understanding of their role as a surrogate of the patient. If this precaution is adopted, then consent will have been appropriately attained no matter the outcome of the capacity assessment: if the patient lacks capacity, then the surrogate would have consented, and if the patient has capacity, then the patient had already consented as well.

It is likely that this additional measure will not be favorably received by physicians who wish to streamline the process of performing a capacity assessment, as it complicates an already complex clinical situation. But this measure appears to be the best procedural solution to the paradox of consent for capacity assessments, as it guarantees that the manners in which we typically obtain consent — either from a patient or a representative — are realized. This "dual consent" model may

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offer other advantages as well. Not only will involving a health care representative address the patient's right to provide consent, but they will also be provided with an early opportunity to engage in the patient's care, likely preventing further issues downstream that are related to decision making. So, while dual-consent for capacity assessments may appear to be an additional hurdle for physicians, this model may be an effective preventative measure against later obstacles in the patient's care. Overall, however, the central message here is that the necessity for obtaining consent follows from the argument outlined above. Recognizing the many tangential issues that will likely arise from the need to obtain consent, the dual consent model is a tentative proposal and leaves open question about the most efficient way of hosting such conversations, or which members of the medical team should be responsible for gathering the different parties. Whatever the case, the implementation of this model would ideally minimize additional time costs for physicians while sufficiently safeguarding patients' rights.

To illustrate, imagine a patient, Mrs. A, who repeatedly declines a capacity assessment, saying that she "doesn't trust those mental tests." This refusal means that her physician no longer has recourse to capacity assessments in order to gauge Mrs. A's role in her own decision-making. The physician cannot (with confidence) turn to Mrs. A for medical decisions; nor can he turn to a health care representative on behalf of Mrs. A without risking infringement upon her personal liberties. This refusal, then, undermines a fundamental component of the physician-patient relationship — namely, respect for his patient's autonomy.

The challenges raised by the refusal of a patient to cooperate with a DMCA, particularly in emergent situations, is not unique to the double consent model, nor to any model that requires informing the patient or obtaining other forms of consent.[22] Appelbaum has pointed out that, in the case of refusal, if one takes refusal to indicate incapacitation, then this may lead to overriding the wishes of patients who may very well have capacity, but who are simply angry, quirky,

Addressing the question itself, then, exposes a fundamental paradox between two principal medical concepts: consent and capacity. This paradox extends beyond theoretical discussions and poses potential difficulties for physicians, especially in cases in which the patient refuses to consent to a capacity assessment. As a resolution, I have proposed that physicians ought to obtain "double consent" for formal capacity assessments from both the patient and their health care representative.

While this model does address the obligation to obtain consent, challenges certainly remain. First, in cases when a patient has no health care representative, physicians would be unable to adhere to the double consent model. The difficulties that arise from such cases, however, stem from the lack of representation itself rather than from double consent model. Such cases import many of the recognized issues that accompany unrepresented and (potentially) incapacitated patients, and so proposing the double consent model does not further require a solution to the issue of unrepresented patients; the issue of decision making for patients who lack a health care representative must be dealt with separately and it falls outside of the scope of this argument. A second challenge to this model arises in cases of patient refusal or the potential refusal of the health care representative. (In fact, it may further complicate the matter since this model introduces a second source of potential refusal.) or overwhelmed. On the other hand, mistakenly presuming capacity may result in providing unwanted medical care without valid consent. Appelbaum then suggests a tentative compromise: clinicians should generally presume capacity in these cases, but in emergent, life-threatening scenarios clinicians may adopt lower thresholds for determining capacity and turn to individuals who are familiar with the patient. For example, if the patient's behavior suggests a lack of capacity and other sources familiar with the patient concur that the patient is incapable of making relevant decisions, then one may infer with reasonable certainty that the patient lacks capacity. Others suggest that the refusal to participate in a capacity assessment should in fact be taken as an indication (though not definitive proof) of that patient's capacity.[23]

Regardless of how we might interpret the refusal of a patient or health care representative to a DMCA, it is worth noting that any case of refusal might be taken

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as an invitation to explore why the patient (or their representative) does not wish to engage in a capacity assessment or in treatment overall. Such situations provide an opportunity to identify the motivation for disagreement. It is likely that the refusal of a capacity assessment is a precursor to long series of refusals to proposed interventions, and so obtaining consent for a capacity assessment serves as a litmus test for the patient's or their surrogate's willingness to work with the medical team in the future.

IV. Conclusion

I have proposed that the largely neglected question of whether clinicians should obtain consent for capacity assessments gives rise to unique conceptual and practical issues. In clinical practice, capacity assessments are an element of care that requires the explicit consent of the patient. However, obtaining consent for capacity assessments gives rise to a paradox: one must have and exhibit capacity to consent, yet one must consent in order to be recognized as having capacity to make health care decisions. Addressing the question itself, then, exposes a fundamental paradox between two principal medical concepts: consent and capacity. This paradox extends beyond theoretical discussions and poses potential difficulties for physicians, especially in cases in which the patient refuses to consent to a capacity assessment. As a resolution, I have proposed that physicians ought to obtain "double consent" for formal capacity assessments from both the patient and their health care representative.

Note

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The Journal of Law, Medicine & Ethics, 47 (2019): 751-757.