Assessing How We Assess Decision-Making Capacity: Informed Consent Is Necessary Before Each Capacity Assessment

By Thomas John Pisano, Jacob Charles Shamash

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Abstract: Decision-making capacity assessments (DMCA) often are made in the setting of a hospitalized patient with questionable mental status. Professional organizations have established that typically, for a patient to be considered to have decision-making capacity, they must demonstrate the following four criteria with respect to their medical condition: 1) ability to express a choice, 2) understanding, 3) appreciation and 4) rational thought. Often a psychiatry consultation is requested for such DMCA, during which patients are not made explicitly aware as to the purpose and consequences of the upcoming interview. Informed consent is present in much of medicine; however, there are no explicit rules to notify a patient of a DMCA before one is made. In addition to the four already established principles in DMCA, we propose one additional rule: interviews must begin with informing the patient as to the nature of the upcoming interaction and inform the patient of their right of refusal related to the assessment.

Psychiatrists are often asked to determine whether a patient has the mental clarity to be in control of their own medical treatments. Professional organizations have established rules for how these assessments are to be made. Often, during these consultations to assess their mental state, patients are not made explicitly aware as to the purpose and consequences of the upcoming interview. The spirit of informed consent permeates through much of medicine. We feel that capacity-assessment consultations should also begin with informing the patient as to the nature of the upcoming interaction.

Key Points

1. Decision-making capacity currently is established using 4 criteria: ability to express a choice, understanding, appreciation and rational thought.
2. The medical field values patient informed consent.
3. There is no formalization of consent in the capacity assessment.
4. We argue that prior to each consent, a patient should be informed about the nature of capacity assessments and their ability to refuse and the consequences thereof.

A cornerstone of medicine is a patient’s autonomy to make their own medical decisions after being appropriately informed (Karlawish & Solomon, 2017). When a patient’s decision-making ability is called into question, a psychiatrist is often charged with the task of administering a decision making capacity assessment (DMCA) to determine whether a patient is of sound mind and judgement to make their own medical decisions. DMCAs involve balancing autonomy with

other ethical tenets: beneficence, non-maleficence and justice, such that medical choices are made objectively in the patient's best-interest.

The criteria for decision-making capacity classically includes (Berg et al., 1996; Karlawish & Solomon, 2017; Schouten, 1999):

1. ability to express a medical choice,
2. demonstration of understanding of their medical situation,
3. ability to appreciate their medical stiuation's relation to their life, and
4. demonstrates reasoning by showing comprehension about consequences of decisions related to their current medical situation.

Yet, there is a striking lack of established protocol to inform the patient that a DMCA will ensue. While most psychiatrists likely begin a DMCA by clarifying the purpose of the interaction, to our knowledge there is no formalized procedure for informed consent (American Psychiatric Association, 2015; Lai & Karlawish, 2007; Tunzi, 2001). Informed consent is a principle present in much of modern society (Appelbaum et al., 1987, Chapter 8; Faden & Beauchamp, 1986) and nearly all physician-patient interactions, but why not CAs?

We cannot expect patients to reasonably refuse DMCAs if they are unaware of what they would be refusing; thus, we propose adding a zeroth DMCA principle to the four previously described:

- Prior to a DMCA, a patient should be informed as to the nature of a DMCA, as well as their right of refusal for the subsequent DMCA.

This rule simply formalizes what many physicians do during DMCAs. By explicitly making it a standard of care to clarify the purpose and nature of the DMCA visit, patients are informed of the procedure that will occur, allowing for increased patient autonomy. One might view this as the Miranda rights (Leong et al., 1988; Oberlander & Goldstein, 2001) of CAs. This rule creates an opportunity for *informed* right of refusal (Annas & Densberger, 1984; Appelbaum et al., 1987, Chapter 11), something patients have with most other medical procedures. If a patient refuses a DMCA after being properly informed of the imminent assessment, then the medical team can assess patient-decision making capacity in a standard manner using collateral information (Hurst, 2004).

Consider the hypothetical situation: a DMCA consult is requested in the emergency department for a patient with bipolar disorder, with a history of medication nonadherence and suicidality. The patient wants to leave against medical advice and will not speak to any healthcare provider, including the consulted psychiatrist. Since a DMCA cannot be performed, a "no capacity" decision is made based on collateral information, effectively stripping this patient of autonomy and almost certainly frustrating the patient. Circumstances like this example can erode patients' trust in the medical system and negatively affect the remainder of patients' hospital admissions, perhaps even carrying over to future physician interactions. These issues are more likely to be exacerbated in patients with psychiatric medical conditions. In this hypothetical situation, if the patient was made aware of the DMCA beforehand, they might not have chosen to refuse the interview. Perhaps, in just giving this patient autonomy through DMCA informed consent, a

novel connection could be established. However, even if their interview-refusal decision would not have made any impact on the result of the DMCA, why should informed consent be absent?

In this scenario, one might argue that if a patient is aware that they are being assessed for capacity, perhaps they might display a facade of capacity, effectively deceiving the clinician into falsely deeming a patient capable of medical decision making. However, the very fact that a patient consciously modifies their response is likely an indication of the patient's understanding and appreciation of their medical situation, and thus might be considered inherently possessing capacity (assuming they have intact expression of choice and rational thought). There is always a risk for an actively suicidal patient to deceive a physician by denying their suicidality, especially in the context of a DMCA. However, we still feel that patients deserve informed consent prior to a DMCA. Of course, if danger to self or others is considered after the DMCA, the physician must revoke decision making capacity (Leo, 1999).

Similarities to formal informed consent preceding DMCAs are present when a mental healthcare provider discloses their "duty to warn" obligation during therapy sessions, known as the Tarasoff Doctrine (*Tarasoff v. Regents of University of California – 17 Cal.3d 425 – Thu, 07/01/1976 | California Supreme Court Resources*, n.d.). Typically, a therapist informs the patient of the confidentiality of the session, yet reserves the right to break confidentiality if there is an imminent risk to self or others. (Costa & Altekruse, 1994). This breach of confidentiality is an established standard in most states (Adi & Mathbout, 2018; Karmen Hanson, n.d.). Since the advent of the Tarasoff Doctrine, both duty to warn and informing the patient's of such duties have been debated across much of the medical system, including HIV-diagnoses (Gostin & Curran, 1987) and disabling hereditary diseases (Falk et al., 2003; Godard et al., 2006). The proposed zeroth principle serves as a similar role for the DMCA as does the notification of patients as part of the therapist's duty to warn. The very nature of a therapist's duty to warn theoretically increases the risk that a patient will be less forth-coming during a therapy session, yet, the general consensus in the medical and legal community is that informed consent outweighs this theoretical risk (Adi & Mathbout, 2018; Karmen Hanson, n.d.).

Another criticism of informed consent prior to DMCAs includes the risk for logic circularity: i.e. a patient "objectively" lacking capacity should not be given decision-making rights related to DMCA refusal. However, we argue that collateral obtained from family members should allow the physician to determine a patient's lack of capacity when appropriate. During the process of obtaining DMCA informed consent, a medical professional can gain valuable information about the mental status of a patient. In the vast majority of cases, these two sources of information, that is, the collateral information and the mental status, should converge on an accurate assessment of capacity.

The occurrence of inappropriate loss of decision making capacity is an understudied field, and likely disproportionally affects marginalized populations. The agreement in patient capacity when two separate interviewers use structured capacity assessments, en masse, have Kappa values ranging from 0.74 to 0.87 (Okai et al., 2007). These numbers imply that up to 1 in 4 patients can be inaccurately assessed for capacity and practically speaking DMCA are not always

done using structured form, suggesting an underestimation of inaccurate DMCA. Importantly, this does not take into account disparities that might be associated with marginalized populations. To our knowledge, differences in removal of decision making capacity based on gender, ethnicity, race or sexual identity has not been well studied.

In general, the identity of a patient often influences interactions between a physician and a patient (Woodall et al., 2010). By and large, mental health care disparities in marginalized populations exist (Tseng et al., 2021) and subsequently bear a greater health care burden negatively affecting quality and length of life (Office of the Surgeon General (US) et al., 2001). Low socioeconomic status is a predictor for rates of mental health disease and suicide attempts (Sareen et al., 2011). Patients may respond positively to a physician if they are of the same gender, and negatively if they are not (Peek et al., 2017). In the case of DMCA, a successful assessment is often associated with the assessor's fluency in the language and culture of the patient. (Shah & Heginbotham, 2008). This feature alone has potential to impact minority populations. Gay and lesbian individuals have been shown to report more acute mental health symptoms (Sandfort et al., 2006). Non-hispanic blacks are more likely to be diagnosed with schizophrenia but less likely to receive treatment (K. J. Coleman et al., 2016). Patients with gender incongruence are over six times more likely to be hospitalized for a suicide attempt (Bränström & Pachankis, 2020; Smith et al., 2019) and often with gender-affirming therapy require DMCAs (Bockting et al., 2016; E. Coleman et al., 2012). These statistics suggest that these populations may be more likely to experience an inappropriate loss of decision-making capacity.

We acknowledge that each DMCA is unique, requiring careful physician judgment. Informed consent, in certain circumstances, can be difficult to provide, however, it is ethically essential. Modern medicine has made great strides to separate itself from prior paternalistic physician-patient interactions (Annas & Densberger, 1984). It is imperative to continue diverging from paternalism by *always* providing informed consent. This is especially the case when the stakes are as high as deeming an individual as lacking the basic right of their own medical decision-making capacity. We call on additional work to be done on the relationship between DMCA and marginalized populations.

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