
COMMENTARY

Focusing on Partnership in the Context of Limited Decision-Making Capacity

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Assessments of decision-making capacity have important implications for patients. They determine the extent to which patients can make their own medical decisions and thus exercise autonomy. Formal assessments of decision-making capacity are typically conducted in situations where substantial decisions need to be made; these are the decisions where one might care most about being able to act autonomously. In “The Paradox of Consent for Capacity Assessments,” Koch calls attention to the apparent disconnect between the importance of capacity assessment and the infrequency with which consent is sought before these assessments are performed.¹ Just as it is for other tests or interventions that have important consequences, Koch argues that express consent is ethically important prior to performing capacity assessment. He then argues that the involvement of a health care surrogate (double consent) can help mitigate the paradoxical challenge of undergoing a consent process to determine capacity for consent.

Koch’s position is rooted in the desire to avoid inappropriately depriving capacitated individuals of decision-making privilege and to avoid patients being exposed to testing that is, in some way, intrusive or invasive without consent. Regarding the importance of the latter goal (avoidance of unwanted exposure to testing), Koch develops a thought-experiment involving Super Capacity Assessment Glasses, which

amount to a more physiologic and more accurate version of current capacity assessments. Koch relies heavily on the intuition that use of such glasses to “read” capacity would require consent because of the medical nature of the assessment. Although I do not share this intuition, Koch’s basic concern about inappropriately depriving individuals of decision-making privilege is clearly significant. This commentary will identify several practical issues that temper the force of the argument for more express consent to capacity assessment and articulate some of the ways in which a double consent model may not resolve core challenges.

Koch places a premium on avoiding inappropriate determination of incapacity, in part because of the assumption that such a determination results in an “exclusion from decision-making.” However, this assumption is not always justified. Thoughtful clinicians routinely engage patients without full capacity in decision-making processes as much as possible to maximize the extent to which decisions are authentic² or reflect values that patients hold. This is not to argue that inappropriately considering a patient incapacitated is unimportant or that a determination of incapacity has no consequence. However, the consequence does not have to be as dramatic as is claimed or assumed here. Many individuals found to be incapacitated will be and should be included in decision-making. If they are so incapacitated that they must be completely excluded, it is likely not a case in which capacity assessment is even useful or necessary. In the end, the collaborative element of the double consent approach that Koch advocates is an attractive feature. However, it would seem that collaboration related to the clinical decision itself would be more meaningful than collaboration regarding the process of whether to consent to capacity assessment. Of course, these two

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processes are not mutually exclusive. The issue is how much value double consent for capacity assessment really adds in the context of a commitment to maximizing involvement of the patient in decisions.

A second challenge is that it is not clear why asking questions to assess decision-making capacity should be a privileged form of communication that requires express consent. Clinicians ask questions all the time of patients, the answers to which have important implications. When a cardiologist asks a patient with heart disease, for example, about his or her baseline functional status, his or her answers have important implications regarding treatment options. If a patient reports “not getting around much,” it might have important implications regarding whether the patient is referred for certain surgeries. And while I may tell a patient that I am asking questions about functional

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status to help think through treatment strategies, I do not ask express consent, with all the consequences explained for different answers the patient might give, before asking these questions. In fact, there are almost no clinical situations in which consent to ask questions is commonly employed, despite numerous situations in which answers matter substantially. While Koch argues that capacity assessments are uncommon and thus that consent cannot be implied, the general concept that clinicians routinely ask questions to guide decision-making seems widely understood. It seems very difficult to draw clear lines regarding what kinds of questions require special, express consent.

A third set of challenges relates to the process of “double” or surrogate consent for capacity assessment. In many cases, such a surrogate may not be available. Especially if a patient has been making his or her own health care decisions for some time and is generally high-functioning, the patient may never have identified a surrogate. It may represent a substantial departure from typical care and, for the patient, a profoundly disrespectful suggestion that the patient needs to identify a surrogate who can help determine whether it is reasonable to ask the patient about his or her own decision-making capacity. Importantly,

Koch’s proposal requires routine involvement of a surrogate whenever capacity is in question, because he is equally concerned about a situation in which an incapacitated patient may inappropriately allow capacity assessment as he is about a situation in which a patient refuses the assessment. In many situations, it is unclear exactly how a surrogate would function in these situations. On what basis would a surrogate make a decision? We typically rely on surrogates to help translate a patient’s values and interests into a decision that reflects what the patient likely would have chosen. It would be challenging to apply such a standard to a capacity assessment decision. It seems as if the surrogate in a double consent model for capacity assessment would be functioning more as a second capacity assessor. Yet it is not clear that a surrogate is qualified to play this role, and it is not obvious what should happen if a surrogate refuses to agree to allow the patient to be exposed to capacity assessment. Are we just to take the surrogate’s word for it that the patient has capacity?

Capacity assessment has important implications, and we generally require consent for tests or interventions that have important clinical stakes. However, the answers to many questions clinicians ask have important implications, and it is not obvious that performing capacity assessment requires such a distinct approach. Moreover, operationalizing a double consent requirement routinely and meaningfully in clinical practice is fraught with complications, and real challenges exist regarding how to handle a situation in which a surrogate refuses such an assessment. If the ultimate goal is to maximize respect for patients’ autonomy and promote authentic treatment choices, it would seem most productive to focus first on strengthening processes for shared decision-making with patients and surrogates in situations where patients have limited decision-making capacity.

Note

The author has no conflicts to disclose.

References

1. P. Koch, “The Paradox of Consent for Capacity Assessments,” *Journal of Law, Medicine, and Ethics* 47, no. 4 (2019): 751-757.
2. D. Brudney, “Choosing for Another: Beyond Autonomy and Best Interests,” *Hastings Center Report* 39, no. 2 (2009): 31-37.