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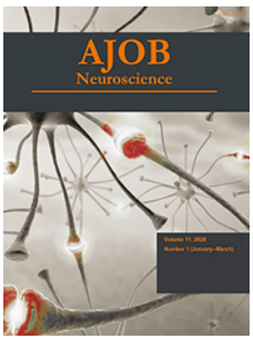

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GUEST EDITORIAL

A Narrative Coherence Standard for the Evaluation of Decisional Capacity: Turning Back the Clock

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In the target article of the present issue, Goldberg (2020) challenges the traditional four criteria for the evaluation of clinical decision-making capacity (understanding, appreciation, ability to reason, communication of decision) by arguing "that clinicians and bioethicists who evaluate decisional capacity face questions far deeper than the mere presence or absence of a patient's informed consent" (7), and that "an additional standard beyond the existing cognitive criteria – to be called the Narrative Coherence Standard" is needed (9).

Goldberg's argument reflects what is sometimes considered a "narrative turn" in parts of medicine and particularly in medical ethics over the last two decades (see Charon and Montello, 2002). We agree with what we take to be the central premise of that movement, i.e., that a focus on patients' narratives can be important in helping clinicians to achieve better understanding of their patients and assisting patients to view their current situations in the broader context of their lives. As Bruner (2002) has suggested, narratives open up a space for self-reflection and self-construction by requiring persons to make sense of their experiences. "Becoming involved in storytelling seems to bring together emotion and thinking, or the essentials of both, in intuitive and analytical reasoning, fostering self-reflection and ultimately self-understanding" (Hermann et al. 2017, 321).

However, a number of authors have also pointed to the limits of narrativity for biomedicine and the medical humanities, particularly with regard to the "frequently unexamined assumption that all human beings are 'naturally narrative'" (Woods, 2011, 73). In his article "Against Narrativity," Galen Strawson takes issue both with the thesis that, in the words of Oliver Sacks, "each of us constructs and lives a 'narrative' … this narrative is us, our identities," and the normative, ethical claim that we ought to live our lives as a story, exemplified by Marya Schechtman's claim that "a person 'creates his identity [only] by forming an autobiographical narrative – a story of his life,' and must be in possession of a full and 'explicit narrative [of his life] to develop fully as a person'." (Strawson, 2004, 428). The former contention is empirically incorrect, whereas the latter unjustifiably demands that persons impose a narrative on their lives or be seen as less than fully human.

Notwithstanding these problems, Goldberg (2020), reflecting the current enthusiasm for narrative approaches, identifies what he takes to be deficiencies in the current approach to assessing decisional capacity and identifies a requirement for narrativity as the corrective. We note, however, that neither of the patients he briefly presents supports a clear case for the inadequacy of the dominant approach to capacity assessment and hence the addition of a narrative criterion. An elderly, depressed woman who believes she is "not worth helping" and apparently discounts the potential impact of the proposed treatment fails to appreciate both the nature of her situation—as a human being, she is indeed worth helping—and the effect of the choices before her, and should be found incompetent under the current criteria. A young, homeless man who arrives in an emergency room in renal failure, "lethargic, with imbalanced electrolytes" (he is later also described as depressed) seems unlikely to meet criteria for decisional capacity, although without further details it is difficult to know with certainty.

Putting aside these specific cases, there are indeed clinical situations in which the current criteria for decisional capacity seem at first sight to be insufficient. As an example, it is known that emotions have a crucial function in decision making. For instance,

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patients with lesions in the ventromedial prefrontal cortex, described at length by Antonio Damasio (see Appelbaum, 1998; Damasio, 1994), seem to lack the emotional responsivity that would allow appropriate decisions to be made. Tranel, Bechara, and Denburg (2002) have described cases in which, after tumors had been resected from the frontal lobe, patients showed a lack of emotional processing and at the same time, intact cognitive functioning. "Despite their fully restored intellectual capacities, these patients make disastrous decisions in complex everyday situations by virtue of their "hard-wired" inability to incorporate affective cues into their decision-making process" (Hermann et al. 2016, 3). As one of us has argued elsewhere (Appelbaum, 1998), however, it has never been clear that these people would not be identified as decisionally incapable under current criteria, nor that the problem is common enough and the relevant impairment in emotional capacity can be defined with sufficient clarity and assessed with adequate reliability to warrant incorporation into the traditional set of criteria for decisional competence.

Even if we were to agree with Goldberg's critique of current approaches (2020), though, we are similarly skeptical of his proposal to add a "narrative coherence standard" to the traditional criteria for competence for three reasons: (1) the lack of evidence of a practical need for a change, (2) the likely performance of the new criterion, and (3) the probable consequences of adding the criterion.

With regard to the first concern, we believe that most of the problems ascribed to current approaches can be addressed within the existing framework for the evaluation of decisional capacity. A "modification might be needed if existing criteria are likely to lead to errors of two sorts: False-positive determinations (i.e., finding someone incapable who actually has capacity), or false-negative findings (i.e., considering someone capable when capacity is actually lacking)." (Appelbaum, 2017, 326). However, neither Goldberg nor any of the other authors proposing changes to current approaches to decisional capacity evaluation have attempted to quantify the frequency with which the alleged deficiencies of current approaches are evident. Moreover, as in Goldberg's article, when the cases said to reflect such deficiencies are examined more closely, the problem seems to reside more in confusion about how to apply the current criteria than in any failing on the part of the current standards.

As for our second concern, the performance of the new proposed criterion, before making a change we would want to know: "[i]ts sensitivity in correctly identifying people with impairment, its specificity in avoiding labeling unimpaired people as incapable, and the reliability with which it can be applied (i.e., whether different assessors are likely to come to the same conclusion about the same person)." (Appelbaum, 2017, 326). These are all empirical questions for which no data are offered. We note our concern about reliability in particular. Is a patient's account of the place of the current decision in the arc of his or her life sufficiently coherent to permit the patient to make a choice with life-and-death implications? The strong likelihood is that different clinicians will have very different responses to that question, depending in no small part on whether they favor or oppose the patient's choice. Such an approach risks turning back the clock to a time when vague criteria led to impressionistic judgments by physicians that deprived patients unjustifiably of their decision-making rights.

Finally, we turn to the consequences of such a change. The proposed narrative coherence standard stands in opposition to the assumption of liberal societies that deprivation of decision-making powers should be a rare event that requires substantial impairment of the relevant capacities. How many of us would feel comfortable with a situation in which a person "who understood the relevant facts, appreciated the nature of his situation, and demonstrated a grasp of the comparative consequences of the treatment options … [was] deprived of his right to make a decision about medical treatment"? (Appelbaum, 2017, 327) Are we truly prepared to demand that someone like that be stripped of the power to control what happens to his or her body because of a failure to coherently "weave together facts and events in such a way that not only gives them temporal sequence, but also laces them with plot development and overarching meaning"? (Goldberg, 2020, 11) And even if we can think of an example in which we might answer that question affirmatively, are we ready to generalize that requirement to every medical patient?

There is a reason why standards for decisional capacity largely have been developed by judges, who are imbued with the importance of individual rights, rather than by novelists, for whom narrative is the dominant consideration. We tinker with the balance struck over many years between our paternalistic impulses and our liberties only at our peril. Patients who can express their lives in coherent narratives are to be admired; those who cannot should be spared the humiliation of having someone else make their decisions for them.

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