

Virtual Mentor

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OP-ED

Perspective Taking and Advance Directives

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I have often wondered if we are asking patients the right question when they create advance directives. We generally ask them to focus on their own preferences and values in deciding what medical treatment choices should be made if they lose the ability to make these decisions for themselves. Then we rely heavily on surrogates to make the real-time decisions because the advance directives are not specific enough or require interpretation. And we expect their choices to reflect what the patient would choose.

Yet research consistently shows a gap between what patients say they want, and what surrogate decision makers say the patients would want. For example, a 2006 review suggests that surrogates incorrectly predict patients' end-of-life treatment preferences in one of every three cases [1]. Additionally, surrogates experience significant burdens when making health care decisions for others, particularly when they are uncertain about, or in disagreement with, what they think the patient would have chosen [2, 3].

One way we understand this is to say that surrogate decision makers do not know patients' preferences, end-of-life choices, or values as well as we thought they did and think they should. Remedies generally focus on encouraging more explicit conversation between loved ones. But this too has proven disappointing. Prior discussion fails to improve surrogates' predictive accuracy [1].

How then might we improve this situation so that patients' and surrogates' decisions line up better? Recently, I began to wonder if neuroscientific findings in cognitive, social and moral decision making might offer a different solution. I was thinking specifically about findings which suggest that decision making aimed at fulfilling a self-directed desire activates different neural networks on fMRI imaging of the brain than morally guided decision making that attends to features of interpersonal relationships. This led me to wonder what might happen if we explicitly asked patients to think about their surrogate decision makers as part of the advance care planning process and to make decisions about future treatments based on what they *would want their surrogate decision makers to decide for them*, rather than solely on what they would want for themselves. Would changing what we ask patients to consider in this regard activate different parts of the decision-making mind? Would it lead to decisions that line up better with what surrogates think they should decide for patients? Would it help close some of the gaps left after advance care planning discussions take place?

Asking individuals to make advance care planning decisions for themselves by putting themselves into the shoes of their surrogates making decisions for them may seem terribly convoluted. It may seem wrong-headed. It certainly moves us some steps away from an autonomy-based model of advance care planning that focuses largely on ensuring that one's own preferences and values are carried forward into a future when one is unable to express them.

What in the neuroscientific literature led me to wander down this path? Findings in three areas caught my eye. First, much about complex decision making occurs outside the realm of consciousness, including mental activities associated with valuing and weighing various alternatives [4, 5]. Indeed, enough good decision making seems to occur “unconsciously” to suggest, albeit controversially, that we harness the power of the unconscious mind to help us make better decisions [6, 7]. Whether or not it is preferable to optimize the role of the unconscious mind, the fact that at least some portions of valuing are not easily accessible to verbal or written communication presents a potential limit to how much explicit discussion is even possible. It may be that there is no way to communicate in writing or orally all of what is important to us. Relying, then, on more or better conversation between patient and surrogate has limited utility.

Second, findings from theory-of-mind and perspective-taking studies suggest that thinking about oneself and about a close other from each other's perspectives (e.g., I think this about me, Mary thinks this about me, I think this about Mary, Mary thinks this about herself) activates overlapping yet distinct neural networks [8]. The perspective one is asked to take matters to the brain even when the topic is the same. Individuals also recruit different neural networks when predicting future intentions of others that involve just one person satisfying his or her own particular goal versus future intentions to involve others in satisfying the goal (“social intentions”) [9]. Thus, thinking about a future activity that involves just me reveals itself on fMRI differently than doing so for an activity that involves me and Mary. One wonders then, what the results would be if we asked individuals to think not about what they would choose for themselves in advance care planning but instead about what they would want someone else to choose for them.

Third, although all complex decision making necessitates the coordination of multiple mental processes, morally guided decisions tap into a distinguishable set of neural networks that do not appear to be activated by decisions based merely on personal desires [10]. Thus, it seems reasonable to wonder if asking individuals to think about what they would want for themselves in the context of advance care planning is more like asking them to think about fulfilling a personal desire or more like asking them to make a morally guided decision. Why does it matter?

Considering what you want for yourself would appear to necessitate neither perspective-taking nor the social and moral aspect of decision making. It could easily involve morally neutral, self-referential components alone. Indeed, the autonomy

model underlying advance care planning generally encourages individuals to focus on their own preferences and values.

Yet these decisions *should* activate both the moral and social mind, since asking someone else to take responsibility for making decisions on one's behalf, particularly of the nature entailed in end-of-life and other significant treatment decisions, is a deeply moral, socially embedded act. The decision about which instructions to leave for someone else to carry forward *should* be viewed in one's mind as a morally guided and socially intended decision, rather than one that merely fulfills private, self-directed values.

Certainly others, after careful normative and empirical analyses, have suggested that these relational features should be attended to more closely [11-13]. And surely it is of no surprise to anyone who has served as, or worked with, a surrogate decision maker that the relational and moral dimensions are there on the back end, when these individuals are asked to step into the shoes of another to carry forward wishes or to make significant treatment decisions. Neuroscientific findings would merely add the possibility that bringing the relational and moral aspects of surrogate decision making into the advance care planning process might more reliably activate social and moral decision-making networks up front, presenting to the mind a fuller picture of what patients actually should plan for.

Of course, the impact that bringing these social and moral aspects into advance care planning might have on the process, experiences, and outcomes of both advance care planning and surrogate decision making warrants study. There is no guarantee that bringing in these aspects up-front would necessarily improve things.

Indeed, it may not change anything. Just because different parts of the brain light up on fMRI does not mean that these differences are scientifically, functionally, or normatively significant [14-16]. That is to say, the lighting up of different parts of the brain during decision making may not change the decisional outcomes; patients' decisions may continue to align only so well with their surrogates'. Or perhaps, in spite of not being directed to do so, we might find that minds of individuals engaged in advance care planning *already* engage in perspective-taking, social intending, and moral decision making. After all, one could construe the mandate to discuss such decisions with loved ones as already bringing their perspectives into the mental process of advance care planning. After such discussions, how could individuals *not* recognize that this other person would be intimately involved in carrying out their advance care plans? And yet, the questions posed on most advance care planning documents direct individuals to think only of their own values and preferences. And maybe this is an important safeguard against losing oneself in the immensity of the social and moral complexities.

But if we have to see it to believe it (or as some might say, believe it to see it), let's get on with it and see what we see when we explore the neuroscientific underpinnings of advance care planning and surrogate decision making. I suspect we

will find that different decision-making networks are involved when we ask individuals to think explicitly about their surrogate decision makers as part of the advance care planning process and to make decisions about future treatments based on what they *would want their surrogate decision makers to decide for them*, rather than solely on what they would want for themselves. And, as long as we are careful not to over- or misinterpret our neuroscientific findings, it's worth taking a look.

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