Promoting the Values for Surrogate Decision-making

The process of making medical decisions used to be straightforward. Clinicians selected the treatment course they determined would best promote the patient’s interests. More recently, in response to increased emphasis on individual autonomy, it is the patient, in consultation with their clinicians and loved ones, who makes medical decisions. This approach respects patients who are able to make their own treatment decisions. However, it poses a challenge for the many adult patients who are unable to understand the information relevant to the decision in question, reason in light of this information and their own values, make a voluntary decision on this basis, or communicate their decision.

To respect these patients who lack decision-making capacity, current practice directs patient-designated and next-of-kin surrogates to make medical decisions based on the patient’s documented preferences (eg, as described in an advance directive). When a patient does not document their preferences, surrogates are instructed to use substituted judgment, trying to make the decision the patient would have made for themselves. When this is unclear, surrogates attempt to promote the patient’s best interests.

Current implementation of this approach is subject to several important shortcomings. First, many patients do not complete an advance directive or otherwise document their preferences prospectively. Second, surrogates frequently cannot predict what treatment the patient would have chosen. Third, the majority of surrogates experience significant emotional distress and burden as a result of making treatment decisions for others. Fourth, because competent adults frequently know what is best for them and make decisions on this basis, respect for autonomy promotes individuals’ best interests. Fifth, permitting competent adults to make their own decisions helps ensure that decisions are made in light of the moral standing of their family and loved ones.

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This ordering from first to fifth reflects the priority of these values, from higher priority to comparatively lower priority. For example, clinicians can offer advice, but they should respect competent patients’ final decisions, even when the decision conflicts with the patient’s personal commitments, revealing that sovereignty takes precedence over authenticity. Similarly, clinicians should not give indicated treatments to unconscious patients when they are known to conflict with the patient’s personal commitments (eg, blood transfusion). This is true even when the patient did not complete an advance directive, revealing that authenticity takes precedence over best interests.

To respect patients after they lose decisional capacity, treatment decisions should continue to be made in...

Five Values Underlying Treatment Decision-making
Respect for autonomy is sometimes understood as a single value. Yet, more recent work in philosophy has emphasized that respecting the autonomy of competent adults promotes a number of distinct values. This work suggests that respect for autonomy promotes at least 5 distinct values. First, permitting competent adults to make their own decisions precludes others from interfering in their lives, thus promoting non-intrusion. Second, respect for autonomy promotes sovereignty, enabling competent adults to direct the course of their lives. Third, because competent adults typically make decisions based on their own personal commitments, respect for autonomy promotes authenticity in the sense of increasing the extent to which individuals’ lives are in accordance with their personal commitments. Fourth, because competent adults frequently know what is best for them and make decisions on this basis, respect for autonomy promotes individuals’ best interests. Fifth, permitting competent adults to make their own decisions helps ensure that decisions are made in light of the moral standing of their family and loved ones.

Opinion

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ways that promote these 5 values to the extent possible. Proposals to revise current practice with respect to surrogate decision-making should thus be evaluated based on whether their adoption would help to promote these (and possibly other) values.

Assessment of the Proposed Modifications to Current Practice
Although the proposals to modify or replace current practice with respect to surrogate decision-making are motivated by valid concerns, they tend to emphasize 1 or 2 of the 5 values at the risk of downplaying or ignoring the others. Supported decision-making aims to promote sovereignty. But, replacing surrogates with a system that permits all patients to make their own decisions, no matter what their level of cognitive function, has the potential to ignore authenticity and best interests. In contrast, limiting surrogate decision-making to promoting authenticity ignores the value of sovereignty.

Given that the proposed modifications do not promote all 5 values, they will need to be revised. Can surrogates be replaced by supported decision-making in a way that goes beyond sovereignty to also promote authenticity and best interests? Can proposals to promote authenticity also respect patient sovereignty? Would supplementation of current practice with artificial intelligence–based algorithms that predict patients’ preferences undermine authenticity for patients who do not want this approach used to determine their care? Pending future research to address these questions, clinicians face the challenge of promoting the 5 values within current practice.

Promoting the 5 Values Within Current Practice
Clinicians working with adult patients who lack decisional capacity should be aware of and try to promote the 5 values to the extent possible. Because sovereignty and authenticity take priority over the moral standing of the family, patients’ advance directives should be followed, even when the family disagrees with the patient’s choices. Exceptions should be made only when there is compelling evidence that following the advance directive would fail to promote sovereignty (eg, it was based on mistaken information) or authenticity (eg, it is out of date).

Current advance directives are designed to document patients’ treatment preferences. To further promote sovereignty and authenticity, clinicians should encourage patients to document their process preferences as well: how and by whom should decisions be made for them in the event of decisional incapacity? This documentation should include the extent, if any, to which the patient grants the surrogate leeway to make decisions contrary to the patient’s stated preferences.10

Making treatment decisions for others can be challenging and prompt significant emotional distress and burden.4 Clinicians should encourage patients to consider these demands when designating a surrogate. Who can best process complicated information, handle stress, and accept responsibility?

When the patient’s treatment preferences are unknown, current practice directs surrogates to make the decision that the patient would have made for themselves.1 To better promote authenticity, clinicians might characterize substituted judgment in terms of what decision best accords with the patient’s personal commitments. Consideration of the personal commitments of similar patients can help to identify these decisions and thereby help reduce surrogates’ decisional burden.2

Surrogates should be encouraged to include the patient in the decision-making process to the extent of the patient’s abilities and interest. In particular, individuals who lose decisional capacity may retain the capacity to form and communicate personal commitments. In addition, soliciting the patient’s assent and respecting their dissent can help to maintain a measure of sovereignty and help to protect the patient’s interests.

Conclusions
Respect for autonomy is sometimes understood as a single value. In fact, respect for autonomy promotes at least 5 distinct values: non-intrusion, sovereignty, authenticity, best interests, and moral status of family and loved ones. This conclusion reveals that proposals to modify current practice with respect to surrogate decision-making, which tend to focus on promoting 1 or 2 of these values, will need to be revised. In the meantime, clinicians should be aware of and try to promote these 5 values within current practice, making efforts to understand, respect, and honor the values and preferences of each patient.

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