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## **Can we improve Treatment Decision-Making for incapacitated Patients?**

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# Can We Improve Treatment Decision-Making for Incapacitated Patients?

by ANNETTE RID AND DAVID WENDLER

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When patients cannot make their own treatment decisions, surrogates typically step in to do it for them. Surrogate decision-making is far from ideal, of course, as the surrogate may not know what the patient prefers or what best promotes her interests. One way to improve it would be to arm surrogates with information about what patients in similar circumstances tend to prefer, allowing them to make empirically grounded predictions about what their patient would want.

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Clinical practice relies on patients to make their own treatment decisions, typically in consultation with a clinician. This approach is intended to respect those who can make decisions<sup>1</sup> but poses a dilemma for incapacitated patients, such as those with advanced Alzheimer disease. This dilemma is widespread. In the United States, approximately half of all decisions regarding life-sustaining treatment for nursing home residents and three-quarters of decisions for hospitalized patients with life-threatening illnesses involve incapacitated patients.<sup>2</sup> These situations pose significant challenges, especially when it is unclear which treatment the patient prefers, and which treatment best

promotes the patient's clinical interests. For example, should clinicians intubate a patient with moderate Alzheimer disease who has no advance directive and develops pneumonia? Current practice in these cases is to rely on the patient's surrogate to make treatment decisions in consultation with the patient's clinicians. Patients sometimes designate a surrogate using a durable power of attorney. State statutes identify next-of-kin surrogates for incapacitated patients who did not appoint a surrogate.<sup>3</sup>

This practice has been in place for more than two decades now, yet there have been no systematic evaluations of how well it promotes the most important ethical goals relevant to making treatment decisions for incapacitated patients. In this article, we describe these goals and argue, based on empirical data from the past twenty years, that in many cases current practice systematically fails to promote them. Then

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we consider various ways to improve current practice. We conclude that incorporating empirically grounded predictions about the individual patient's treatment preferences into the shared decision-making process offers the greatest potential to promote the ethical goals relevant to making treatment decisions for incapacitated patients.

### Six Ethical Goals

Treatment of incapacitated patients sometimes raises concerns about how to distribute limited medical resources. The burdens clinicians experience also raise questions regarding possible limits to their obligations to care for incapacitated patients. Recognizing the relevance and importance of the claims of both clinicians and society, the people most affected in this context are the patient and the patient's family and loved ones. This article focuses on their claims and interests.

Treatment decision-making for incapacitated patients should help to promote respect for patients' autonomy and beneficence for patients, their families, and their loved ones. To realize these ends, decision-making should:

- 1) promote the patient's clinical interests;
- 2) enable the patient to control how he or she is treated;
- 3) provide treatment consistent with the patient's preferences and values;
- 4) respect the patient's preferences for how treatment decisions are made;
- 5) respect and help the patient's family and loved ones; and
- 6) promote timely decision-making.

Commentators often focus on possible conflicts among these six goals. What should be done when the patient's treatment preferences conflict with his or her clinical interests? What should be done when the patient's treatment preferences conflict with his or her family's interests? These conflicts raise important theoretical questions regarding which goals should take priority and whether trade-offs can be acceptable. But in practice, it is often not clear how to realize *any* of these goals. The practically important question, therefore, is: To what extent does current practice promote the six ethical goals for treatment decision-making that are attainable in the given situation? A significant body of empirical data

them against the burden of continued care.

Ideally, these cases would be resolved by appeal to a method that would help to identify the best course of medical treatment. But such a method does not exist. If even expert clinicians are unsure which treatment is best, there is currently no other authority on the matter. In a significant number of cases, it is therefore unclear which course of treatment would best promote the patient's clinical interests. In these cases, it is unlikely that *any* method of making treatment decisions will be able to consistently promote the patient's clinical interests.

*Enabling the patient to control how he or she is treated.* Advance

**Commentators often focus on possible conflicts among the ethical goals for treatment decision-making, such as when a patient's treatment preferences conflict with her clinical interests. But in current practice, it is often not clear how to realize *any* of these goals.**

collected over the past twenty years provides the opportunity to answer this question.

### Evaluating Current Practice

*Promoting the patient's clinical interests.* Current practice works well when it is clear which treatment best promotes the patient's clinical interests, and there is no evidence that the patient would not have wanted that treatment. There are a significant number of cases, however, in which the patient's clinicians are unsure which treatment would best promote the patient's clinical interests. Decisional incapacity arises most frequently in the context of severe injury, progression of serious disease, and dementia. In these cases, it is often difficult to predict and evaluate the outcomes of treatment and weigh

directives provide a mechanism by which patients can guide the treatments they will receive if they lose the ability to make their own decisions.<sup>4</sup> When an incapacitated patient has completed a valid advance directive, and the directive applies to the given situation, current practice enables patients to prospectively control how they are treated. Unfortunately, despite extensive efforts to increase completion rates, most patients do not complete an advance directive or otherwise document their treatment preferences.<sup>5</sup> Moreover, completed advance directives often do not provide clear guidance for how the patient would want to be treated.<sup>6</sup> As a result, current practice often fails to promote this goal.

*Providing treatment consistent with the patient's values and preferences.* To provide treatment consistent with the patient's values and

preferences, current practice appeals to the patient's advance directive. In the absence of a valid directive, surrogates are asked to select the treatment option they believe their loved one would have chosen if he or she were able to decide.<sup>7</sup> Yet a review of the existing data, involving 19,526 paired patient-surrogate responses to hypothetical treatment scenarios, found that patient-designated and next-of-kin surrogates correctly predicted patients' treatment choices only 68 percent of the time. Since most of the scenarios offered binary choices, random guessing would have been correct approximately 50 percent of the time. In addition, the treatment offered in many of the scenarios clearly was in the patient's clinical interests. These data suggest that surrogates' predictions are only slightly better than chance in cases where it is unclear which treatment option would best promote the patient's clinical interests.<sup>8</sup> This finding has been confirmed by more recent studies.<sup>9</sup>

One might hope that surrogates are more accurate in actual circumstances, compared to the hypothetical scenarios used in the empirical studies. In particular, real cases provide essential details and convey the seriousness of treatment decisions, which might increase the accuracy of surrogates' predictions. While this is a possibility, there is reason to believe that the stress and anxiety associated with making treatment decisions for incapacitated loved ones<sup>10</sup> will decrease, rather than increase, surrogate accuracy.

In addition, empirical studies—including a randomized, controlled trial of 408 patient-surrogate pairs<sup>11</sup>—find that the two most promising options for improving surrogate accuracy are ineffective. Neither appointing one's own surrogate nor discussing one's treatment preferences with the surrogate improves the predictive accuracy of surrogate decision-makers.<sup>12</sup> One might also hope that surrogates could do better if they were coached on how to make treatment decisions and, in particular, informed of

common decisional biases, such as projecting one's own treatment preferences on to the patient. However, person-perception studies find that debiasing methods typically are not effective and can even reduce the accuracy of some judgments.<sup>13</sup>

At first glance, it seems surprising that surrogates poorly predict the treatment preferences of their loved ones, including those they have known intimately for decades. However, social psychology and consumer behavior research suggests that surrogate inaccuracy is just one instance of our more general inability to predict the preferences and values of our loved ones.<sup>14</sup> For example, in one study, forty spouses predicted their partners' preferences for twenty different consumer products no more accurately than predictions based on the preferences of the average spouse.<sup>15</sup> Another study found that individuals who have been married a long time are *less* able to predict the views and feelings of their spouses than individuals married a relatively short time.<sup>16</sup>

Predicting a loved one's preferences regarding consumer goods is very different from predicting his or her values and preferences about medical treatment. Peoples' consumer preferences fluctuate significantly, and usually not much is at stake if we choose the wrong tie for dad's birthday. By contrast, patients' treatment preferences are more fundamental, and patients' lives often are at stake when treatment decisions must be made for them. Recognizing these differences, the available data suggest that surrogates' predictions for their loved one's treatment preferences are no more accurate than the predictions for their loved one's consumer preferences. The reason is that the mechanisms undermining our predictive abilities trace largely to general facts about human psychology and human relationships, not to the details of the decisions in question.<sup>17</sup> These mechanisms include:

- **Difficulty processing information:** When trying to predict the preferences of those we know very well, it is difficult to sort through everything we know about them to identify the facts that are relevant to the choice in question.<sup>18</sup>

- **Overconfidence:** We tend to assume that we know the preferences of family and loved ones<sup>19</sup> and, therefore, we bypass the process of attempting to figure out what they would want in the circumstances.<sup>20</sup> Overconfidence also makes it difficult to learn. When confident about a prediction, we tend to reinterpret negative feedback as being consistent with our view, or we ignore it.<sup>21</sup>

- **Assumption of similarity:** We assume that those closest to us share our values. This mechanism is important for maintaining intimate relationships.<sup>22</sup> However, it makes it difficult to separate what *we* want in a given situation from what we think a *loved one* would want.<sup>23</sup> While the assumption of similarity can be appropriate in some cases, data reveal that surrogates' treatment decisions are often guided by different values than the decisions of their loved ones.<sup>24</sup>

In addition to these fundamental psychological mechanisms, the clinical context introduces factors that can further reduce surrogates' predictive abilities.

- **Anxiety:** Deciding whether to implement a medical treatment to keep a loved one alive often causes significant anxiety.<sup>25</sup> For example, of 920 family members visiting patients in intensive care units in France, more than two-thirds were suffering from symptoms of anxiety or depression.<sup>26</sup>

- **Complexity:** Predicting patients' treatment preferences requires surrogates to understand complex medical facts. Many people have

difficulty reasoning about probabilities,<sup>27</sup> which undermines their ability to make decisions based on the patient's medical prognosis.

• **Discomfort with surrogate role:** Trying to predict which treatment is consistent with the patient's preferences can leave surrogates feeling responsible for the outcome.<sup>28</sup> Studies find that surrogates often respond by choosing whichever treatment option minimizes their sense of responsibility.<sup>29</sup>

Given that psychological mechanisms are entrenched and these other factors are inherent to the clinical context, it seems unlikely that we will be able to improve surrogates' ability to predict which treatments their loved one would want. In the absence of a valid advance directive, current practice therefore often will fail to treat patients in a way that is consistent with their preferences and values.

*Respecting the patient's preferences for how treatment decisions are made.* Empirical studies suggest that many patients want their family members to make treatment decisions for them.<sup>30</sup> A qualitative study of seventy-one elderly individuals found that 90 percent wanted their family and loved ones to make treatment decisions for them if they became unable to do so.<sup>31</sup> In a study of eighty dialysis patients, most had not completed an advance directive because they thought family members should make decisions on their behalf.<sup>32</sup> These studies suggest that current reliance on surrogates promotes respect for patients' preferences regarding how treatment decisions are made.<sup>33</sup>

The problem is that many of the patients who have been surveyed want their family members to make treatment decisions for them because the patients assume that their family members know their treatment preferences.<sup>34</sup> For example, most of the patients in one study wanted family members to decide on their behalf because they assumed that "their family knew what they would want."<sup>35</sup>

There are no data on how patients would want treatment decisions to be made if they were informed about the inaccuracy of their surrogates' predictions. Thus, it is unclear whether current practice promotes this ethical goal.

*Respecting and helping the patient's family and loved ones.* A number of studies have assessed the impact on surrogates of making treatment decisions at the end of life.<sup>36</sup> These studies consistently find that many surrogates experience anxiety, stress, depression, and family conflict as a result of making treatment decisions. A minority of surrogates seem to be comforted by the fact that they played an important role in protecting their loved ones.<sup>37</sup>

Anxiety over whether they made the right decision is profound in many surrogates and can last for months—

suggest poignant explanations for this effect.<sup>42</sup> One surrogate reported that she would not wish the experience of making end-of-life treatment decisions for a loved one on her "worst enemy."<sup>43</sup>

Taken together, the existing data suggest that current practice fails to benefit and may well harm many patients' families and loved ones. Because many patients do not want to be a burden on their family and loved ones,<sup>44</sup> these findings raise further questions regarding whether informed patients—those who recognize the extent of surrogate inaccuracy and surrogate burden—would want their family and loved ones to make treatment decisions for them. It may be, then, that current practice fails to respect patients' true preferences for how treatment decisions are made.

## The challenge is to identify an approach to treatment decision-making that retains current practice in cases where it works well but supplements it in cases where it fails.

even years.<sup>38</sup> One study of seventy-four surrogates found that stress levels were "extraordinarily high" compared to the same stress measures in individuals who had experienced ferry or construction disasters, or loss of housing due to fire. The same study reports that, although stress levels had decreased at six months, they "still exceeded the levels in those other traumatic situations."<sup>39</sup>

Some of the stress and anxiety experienced by surrogates is likely part of the grieving process, the stress of the intensive care unit, and the often-inadequate communication with clinicians and other hospital staff.<sup>40</sup> Yet a quantitative study found significantly higher rates of stress and anxiety among twenty-two family members who were involved in making end-of-life treatment decisions, compared to twenty-eight family members who were not involved in these decisions.<sup>41</sup> Qualitative studies

One would hope that some of the stress and anxiety that surrogates experience as a result of helping to make medical treatment decisions can be alleviated. Ongoing efforts focus on improving clinicians' communication skills<sup>45</sup> and their ability to provide emotional support,<sup>46</sup> as well as emphasizing shared responsibility between clinicians and surrogates for the decision-making process and the final treatment decision.<sup>47</sup> Several studies also show that surrogates often experience significantly less stress—and some even benefit—when they believe that they selected the treatment option the patient would have chosen.<sup>48</sup> These data suggest that improved communication and shared decision-making benefits surrogates in some—but not all—possible ways. To further support them, we need a way to help surrogates predict which choice the patient would have made.

*Promoting timely decision-making.* To our knowledge, there are no empirical studies on how long it takes surrogates to make treatment decisions. However, empirical studies show that conflict about treatment decisions is frequent, occurring in at least a third of all cases.<sup>49</sup> Assuming that disagreement prolongs decision-making, these data suggest that current practice likely does not promote timely decisions.

The above analysis suggests that current practice works well when clinicians know which treatment promotes the patient's clinical interests, and families do not have reason to believe that receiving that treatment is contrary to the patient's preferences and values. Current practice works less well when it is not clear how to promote the patient's clinical interests, and the patient's treatment preferences are unclear or unknown. This analysis presents the challenge of identifying an approach to treatment decision-making that retains current practice in the cases where it works well, but supplements it in cases where it fails to promote the six ethical goals for treatment decision-making.

### Alternative Approaches

A number of modifications to current practice have been proposed. The most widely endorsed is shared decision-making between clinicians and surrogates.<sup>50</sup> As discussed, shared decision-making is likely to alleviate at least some of the stress and anxiety that surrogates experience, and patients may prefer shared decision-making over current practice for this reason. Yet shared decision-making is unlikely to promote the goal of providing treatment that is consistent with the patient's preferences and values. In particular, empirical studies find that physicians are even less accurate than surrogates at predicting patients' treatment preferences.<sup>51</sup> Presumably, combining two inaccurate decision-makers will not increase the chances that incapacitat-

ed patients receive the treatment they would want.

Some commentators endorse narrative approaches to treatment decision-making,<sup>52</sup> focusing on making treatment decisions that continue the patient's life story. While this approach makes sense, continuing a patient's life story largely would be realized by making decisions consistent with the preferences and values that guided the individual's life. As we have seen, this goal has been very difficult to promote.

Commentators have also proposed alternatives to current practice that would reduce the role of surrogates in the treatment decision-making process. For example, some suggest having treatment decisions made by physicians alone.<sup>53</sup> This approach is likely to result in timely decisions, but it fails to promote the other ethical goals for treatment decision-making. Physicians predict patients' treatment preferences even less accurately than surrogates,<sup>54</sup> and most patients do not want treatment decisions to be made solely by their clinicians. Moreover, excluding surrogates from the decision-making process fails to respect them and their important standing in patients' lives.

Other commentators suggest that treatment decisions should be made by ethics committees or judges.<sup>55</sup> Data suggest that strangers predict loved ones' preferences more accurately than family members or loved ones.<sup>56</sup> These data provide some reason to think that courts or institutional ethics committees might better promote the goal of providing treatment consistent with patients' preferences. However, courts and ethics committees require considerable time to be convened and to familiarize themselves with a given case, thus undermining the goal of timely decision-making. Relying on courts and ethics committees would also distance patients' families and loved ones from treatment decision-making, which fails to respect most patients' preferences regarding how treatment decisions are made.

Finally, some commentators have endorsed basing treatment decisions for incapacitated patients on the preferences of patients in the same community.<sup>57</sup> This approach could promote timely decision-making, assuming the requisite data are collected ahead of time. Yet basing treatment decisions on the preferences of other patients in the same community is unlikely to identify the treatment option most consistent with the patient's preferences and values unless the community happens to be very homogenous, at least with respect to values and preferences regarding medical care. A community-based approach also removes patients' surrogates from the decision-making process, and thus is unlikely to respect patients' preferences for the decision-making process.

### A Proposal for Supplementing Current Practice

Of the proposed alternative approaches to current practice, decision-making that is shared between surrogates and clinicians seems to offer the greatest potential for supplementing and improving current practice in cases where the patient's clinical interests and treatment preferences are unclear. Shared decision-making allows surrogates to be involved in the care of their loved one and to protect their loved one from abuse while gaining the benefit of clinicians' medical expertise. Moreover, a sense of shared responsibility for the final treatment decision is likely to reduce surrogates' stress and anxiety. These advantages should also increase the chances that clinicians will support shared decision-making. In addition, shared responsibility would probably relieve clinicians' own torments. The collaborative spirit of shared decision-making might also allow clinicians to reduce misunderstanding and conflict with surrogates. This should help to promote the patient's clinical interests.

Recognizing these advantages, shared decision-making fails to

address the problem that often neither surrogates nor clinicians know which treatments are consistent with the patient's preferences and values. This problem can undermine three of the six ethical goals for treatment decision-making. Insufficient knowledge of the patient's treatment preferences reduces the chance that the patient will be treated in a way consistent with his or her preferences and values. It also leaves families still stressed about identifying their loved one's preferred treatment option and likely delays treatment decisions. In light of these considerations, patients may well prefer some other approach to treatment decision-making. But to supplement current practice and further improve treatment decision-making for incapacitated patients, we must consider how surrogates and clinicians can better predict which treatments are consistent with the patient's preferences and values.

One possibility would be to predict which treatment the patient would have chosen based on his or her individual characteristics and features of the treatment options. Data reveal that patients' treatment preferences often correlate with their individual characteristics, especially age,<sup>58</sup> gender,<sup>59</sup> and race.<sup>60</sup> The characteristics of a given treatment option—such as the burden it imposes on the patient<sup>61</sup> and the patient's expected state of health after treatment<sup>62</sup>—also influence how people want to be treated during periods of decisional incapacity.

These data point to the possibility of predicting how a given incapacitated patient would want to be treated based on his or her individual characteristics, the situation, and how these factors influence people's treatment preferences. To create a tool for predicting patient preferences, it would be necessary to gather extensive empirical data from a representative sample on how individuals want to be treated in common situations involving decisional incapacity. Statistical analysis of these data would identify predictors of patients'

treatment preferences that would be used to construct an algorithm to predict the treatment preferences of individual incapacitated patients. The resulting predictions could be incorporated into the shared decision-making process in situations in which the patient's treatment preferences are unknown, and which treatment would best promote the patient's clinical interests is not clear.

### Advantages

Incorporating predictions of the individual patient's treatment preferences has the potential to significantly improve treatment decision-making. First, empirical data suggest that algorithmic predictions of patients' treatment preferences are likely to be more accurate than surrogates, thus promoting the goal of treating patients in a way consistent with their preferences and values. In

Second, incorporating predictions about the patient's treatment preferences into the shared decision-making process has the potential to significantly reduce surrogates' stress and anxiety. As discussed above, having to guess which treatment is consistent with the patient's preferences and values is a significant cause of stress and anxiety for many surrogates. Using preference predictions could help surrogates to more accurately identify their loved one's preferred treatment option, alleviating this stress and anxiety and possibly reducing the extent to which surrogates feel personally responsible for the ultimate outcome.

Third, patients are likely to endorse incorporating preference predictions into the shared decision-making process if this reduces the stress and burden on their loved ones and increases the chances that they will receive treatment consistent with

## Data point to the possibility of predicting how a given incapacitated patient would want to be treated based on her individual characteristics like age, gender, and race, her situation, and how these factors tend to influence treatment preferences.

one study, the average treatment preferences of 401 individuals were as accurate a predictor of any individual's treatment preferences as the patient's chosen surrogates.<sup>63</sup> A second study found similar results when applying a common view about lifesaving treatment to almost fifty different treatment scenarios used in previous research about surrogate accuracy.<sup>64</sup> These data suggest that the treatment preferences of the *average* person can predict patients' preferred treatment just as accurately as surrogates. Therefore, it is likely that *highly individualized* predictions of patients' treatment preferences will, on average, be more accurate than the predictions made by surrogates.

their preferences and values. If true, using preference predictions would also promote the goal of respecting patients' preferences regarding how treatment decisions are made for them.

Fourth and finally, knowing which treatments the patient is likely to want has the potential to help reduce conflict over treatment decisions. Predicting the patient's treatment preferences may therefore significantly aid timely treatment decisions. These advantages provide compelling reason to pursue future work to evaluate the acceptability and feasibility of using predictions of patients' treatment preferences in practice.

## Open Questions

Before advocating for this approach, it is important to clarify several essential conceptual and normative issues. First, individuals' preferences regarding medical treatment change over time. In order to develop an algorithm for predicting patients' treatment preferences, we must decide which stage of life should form the basis for identifying the preferences and values that guide treatment decisions for incapacitated patients. A plausible assumption is that the patients' last competent preferences are the relevant ones. This approach is consistent with the current practice of basing decisions on the preferences the patient last articulated or recorded.

Second, more research on precisely how predictions of the patient's treatment preferences should be incorporated into the shared decision-making process is also necessary. Should patients be able to mandate that their surrogates do not receive preference predictions? Should the preference predictions be provided to surrogates only when they ask for this information, or routinely to all surrogates? Or should their use be regarded as the default option, to be followed unless the surrogate objects?

Third, future research will also have to examine concerns about stereotyping and abuse. Would preference predictions help to respect patients' individual characteristics, or would they be seen as stereotyping patients? What are the chances that patients' families or clinicians could abuse preference predictions—for example, by using them to justify decisions that promote their own interests over the patient's? What are effective ways to address the potential for abuse?

In addition, extensive empirical work will be needed to develop a sound instrument for surveying people's preferences for treatment during periods of decisional incapacity. What is the best way to survey treatment preferences, and how can a

predictive algorithm be isolated from these data? How accurately can an instrument predict patients' treatment preferences? Further work will also be necessary to assess the impact of incorporating predictions of patients' treatment preferences into the shared decision-making process between surrogates and clinicians. Does incorporating preference predictions reduce the stress and anxiety many surrogates experience from helping to make treatment decisions? What do patients think about different ways of using this kind of information? Provided that using preference predictions can be defended on conceptual and normative grounds, these questions would best be answered in a pilot study.

Among the existing proposals to improve treatment decision-making for incapacitated patients, incorporating predictions of the patient's treatment preferences into the shared decision-making process between surrogates and clinicians appears to have the greatest potential to supplement current practice and further promote the ethical goals for treatment decision-making. Future research will have to determine whether this approach is justifiable, whether it more often leads to treatment choices that are consistent with the patient's preferences and values, what impact it has on surrogates, and whether surrogates and patients endorse it as a supplement to current practice.

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