

## PERSPECTIVES

# Substituted Judgment: The Limitations of Autonomy in Surrogate Decision Making

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Substituted judgment is often invoked as a guide for decision making when a patient lacks decision making capacity and has no advance directive. Using substituted judgment, doctors and family members try to make the decision that the patient would have made if he or she were able to make decisions. However, empirical evidence suggests that the moral basis for substituted judgment is unsound. In spite of this, many physicians and bioethicists continue to rely on the notion of substituted judgment. Given compelling evidence that the use of substituted judgment has insurmountable flaws, other approaches should be considered. One approach provides limits on decision making using a best interest standard based on community norms. A second approach uses narrative techniques and focuses on each patient's dignity and individuality rather than his or her autonomy.

**KEY WORDS:** decision making; end-of life; substituted judgement; surrogate.

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## BACKGROUND

Physicians who care for seriously ill patients are all too familiar with making crucial health care decisions when the patient lacks decision making capacity. In such cases, surrogates, usually family members, must help guide decisions. Several ethicists have described a standard, stepwise approach that is based foremost on the principle of autonomy. This approach starts by turning to the patient's advanced directives.<sup>1-3</sup> When there is no advanced directive, we appeal to the concept of substituted judgment, asking what the patient would have wanted if he or she could tell us. If we have no information about a patient's prior wishes, we rely last of all on the standard of best interests.

Since many patients do not have advance directives,<sup>4</sup> or existing directives do not apply to the decision at hand, substituted judgment must frequently be evoked in decision making. The philosophical appeal of this standard is that it

supports the patient's autonomy by leading us to the decision that the patient would have wanted. Several authors have argued that substituted judgment does not succeed in meeting this goal.<sup>5-8</sup> In spite of these arguments, substituted judgment remains the guiding framework for surrogate decision making in both bioethics and law.

We believe that a compelling argument against substituted judgment can be made based on empirical evidence and that this evidence points us to ethical models that are more consistent with the reality of patient care. As Sulmasy and Sugarman point out in regard to surrogate decision making, theoretical approaches are not useful in the clinical setting if they are impossible to carry out.<sup>9</sup> Since the theoretical framework for surrogate decision making was developed, research has shown that the concept of substituted judgment rests upon false assumptions and is unable to meet the stated goals of maintaining patient autonomy.

Below, we review the evidence against substituted judgment, and then the reasons we adhere to this flawed approach. We then explore newer approaches to end-of-life decisions for patients without advanced directives that meet our moral ideals and are consistent with findings of empirical studies. Re-imagining the rationale for end-of-life decision making may give us a more accurate, more honest, and ultimately more useful framework for making these complex decisions.

## THE EVIDENCE AGAINST SUBSTITUTED JUDGMENT

Three separate but related lines of research show the weaknesses of substituted judgment. The first is a series of studies that show how individuals' own preferences regarding life-sustaining treatment change over time.<sup>10-13</sup> In such studies, people are given health scenarios and asked whether they would want certain medical interventions. They are then resurveyed at later times. These studies show that many individuals change their own wishes with regard to life-sustaining treatment over time.<sup>10-12</sup> In one study over half of patients who initially said yes to a series of medical procedures changed their minds over two years.<sup>13</sup> Furthermore, mind-changing is not random. Individuals who fill out an advanced directive are less likely to change their wishes than those who do not.<sup>10,13</sup> Thus, the patients who most need substituted judgment, because they lack a living will, are the ones for whom it is least likely to be accurate.

A second line of research examines the concordance between a patient and his or her doctors,<sup>14-24</sup> or chosen surrogates.<sup>17,18,21,25-32</sup> In such studies, individuals are asked

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what they would want for themselves in particular circumstances. Their loved ones or designated proxies are then asked to predict what the patient would have wanted. A recent meta-analysis of surrogate predictions found that surrogates are correct about 68% of the time.<sup>33</sup> Studies have tried to improve the accuracy of surrogate decisions by facilitating conversations and providing instructional materials. They have generally been unsuccessful<sup>32</sup> or have improved predictions only modestly.<sup>14,19</sup>

Finally, there has been extensive research examining whether patients really want their prior wishes to be the sole basis for decisions made on their behalf. This research reveals that the majority of patients prefer that family members or physicians have input into the decisions.<sup>34–38</sup> In these studies, as in the ones examining the stability of patients' preferences, the patients who were most likely to want their wishes to prevail were the ones who more often wrote advanced directives.<sup>38</sup>

## WHY DO WE STILL TURN TO SUBSTITUTED JUDGMENT?

In spite of these robust and consistent studies, many physicians and bioethicists rely on the concept of substituted judgment. Why is this?

Autonomy is a fundamental value in our society and in our bioethics. The move from paternalism to an autonomous framework for patient decision making has arguably been the most important change in medical ethics in the past 30 years. Self-determination has become the central guiding principle in medical decision making. We therefore strive to ground all decisions in autonomy, even when the patient is no longer able to express an autonomous wish.

This preference for an autonomy-based moral framework comes not just from philosophy but from law. In a series of decisions involving end-of-life care, the courts invented and have relied upon the notion of substituted judgment. In the 1976 case of *Karen Quinlan*, the New Jersey Supreme Court determined that Quinlan should not lose the right to refuse medical treatment even though she had lost her decision making capacity. In such cases, a surrogate could refuse on her behalf.<sup>39</sup> The *Cruzan* decision in 1990<sup>40</sup> examined the question of artificial hydration and nutrition and concluded that a state may require "clear and convincing evidence" of patient's preferences prior to the withdrawal of such therapy (only two states currently require this). Court decisions such as *Quinlan* and *Cruzan* reflect our society's strong emphasis on individual liberty. Specifically, they are an attempt to respect the individual's autonomy, even when he or she can no longer make medical decisions. We hope that our review of the evidence has shown that these efforts, although well intentioned, have been largely unsuccessful.

Substituted judgment also has psychological benefits. There is evidence that families feel a tremendous burden when making life and death decisions for a loved one.<sup>41–45</sup> An appeal to substituted judgment may remove some of the burden, by framing the decision as the patient's own choice rather than the surrogate's. When a family is in dispute with each other or with physicians about a decision for an incompetent patient, an appeal to substituted judgment can also change the focus of the discussion from the desires of the family members to those of the patient. This strategy can help focus the con-

versations away from family tensions or surrogate needs and toward the needs and wishes of the patient.

These explanations for the durability of substituted judgment, however, overlook much of what we've learned about the way people deal with end-of-life decisions and understand one another's desires. We propose two alternative models that acknowledge both the importance of the individual and the fact that that person is dependent and non-autonomous during critical illness.

## ALTERNATIVE MODELS OF DECISION-MAKING

### Best-interest Standards Based on Community Norms

Rebecca Dresser has proposed that we develop objective standards for best interest that are based on community norms.<sup>6</sup> Such an approach would require a public discussion about end-of-life care and agreement that limits would be set on the individual surrogate's leeway in decision making. This would contribute to end-of-life decision making in two possible ways. First, community standards could set limits on the types of choices surrogates can make. This becomes particularly important when surrogates request treatment that physicians think is extreme or inappropriate. These situations, although rare, account for much of the debate in the courts and the media over the appropriate role of surrogates. Second, a community standard-based approach could lead to the development of system-wide pathways for end-of-life care that could be applied to all patients, rather than determined at the bedside of each individual patient.<sup>8</sup> Such a standard is consistent with the research that shows we cannot accurately predict the wishes of individual patients. This proposal has two limitations. First, the process of reaching public consensus about health care decisions would be lengthy, if it were possible at all. Second, while community standards may place useful boundaries on care, medical decision making is still primarily concerned with the values and interests of each particular individual. The best interest standard is ethically incomplete because it does not consider the patient as an individual or as a member of a unique set of relationships.

### The Patient's Life Story: Respect for Persons

The ethical principle of respect for persons is a broader concept than autonomy. It includes related concepts such as dignity and individuality,<sup>46</sup> and involves the duty to protect patients who cannot themselves make autonomous decisions.<sup>47</sup> An approach to surrogate decision making based on respect for persons may allow us to meet our obligation to consider patient needs above all others, while acknowledging the loss of autonomy that occurs with severe illness.

A narrative approach to surrogate decisions would provide a means to operationalize the concept of respect for persons in clinical practice. Other authors have described the use of this approach in surrogate decision making.<sup>48,49</sup> Surrogates consider the life story of the patient and make decisions that seem consistent in light of the patient's previous choices and experiences. A narrative approach acknowledges that when individuals lose decision making capacity, they can no longer control their health care decisions. This loss of control,

however, does not mean a loss of individuality or dignity. Such basic aspects of a human being can be carried on by loved ones who make decisions for the individual that are consistent with his or her own life choices. By such an approach, surrogates do not try to predict the actual choices that an incapacitated loved one would have made, as they would under substituted judgment. Instead, they make decisions that consider the individual's interests and values in the context of their current situation.

### IMPACT OF THE ALTERNATIVE MODELS

How would these new approaches affect both ethical reasoning and communication with surrogates? This can be best illustrated with a case:

A 76-year-old woman is admitted to the intensive care unit for pneumonia. She develops sepsis with renal failure and a rising potassium level. Her physicians approach her son to discuss whether to initiate dialysis or change the focus to palliative care and comfort. Her son says, "My mother was always a fighter. She wouldn't want to give up." The patient does not have advance directives.

Under the traditional framework, the physician would first inquire about the patient's wishes, with questions such as, "If she were able to be part of this conversation, what do you think she would want to do?" It is consistent with the traditional substituted approach to explore the strength of evidence for the patient's wishes. Did she ever make specific statements about intensive care, dialysis, or her preferences for the time and place of her death?

Using a community based approach, physicians would describe the treatment options that had previously been determined to be acceptable under the circumstances. Physicians may say, "When a person such as your mother develops kidney failure, our hospital and health care system offer comfort care. We would not attempt to resuscitate her if her heart or breathing were to stop." Such an approach sets limits on care, and decreases the range of options offered to the surrogate.

An approach based on respect for persons would focus on several aspects of the patient as a person, including prior wishes, her dignity, and her place in her family and community. This shift in focus would change the approach that physicians take to the conversation. Using narrative techniques, the family may first be asked to talk about the patient's life and how this illness was a part of that life story. This approach allows a deep exploration of statements such as, "Mother was always a fighter." However, because the conditions she is currently facing may be different from any she had encountered, her prior approach to life cannot be assumed to tell us what she would do under the present circumstances.

The process of recounting the patient's life can build a common purpose and understanding among surrogates and health care providers.<sup>50</sup> It retains the psychological advantage of turning attention from the needs and wishes of the patient's loved one's to those of the patient, but maintains a realistic perspective on what we can know about the patient.

A potential limitation of the narrative approach is that it does not provide a clear mechanism for resolving disagree-

ments. There is no objective scale for judging one family member's narrative as superior to another's. However, we argue that in most cases, this approach will lead to consensus about the right course of action and will decrease the need for choosing one surrogate over another. When this approach fails, a last resort is the legalistic approach of giving decision making authority to one surrogate over the objections of others. Many state laws specify such a hierarchy.

### THE FAMILY AS BOTH PATIENT AND DECISION MAKER

A shift away from substituted judgment would lead to a different moral approach to end-of-life decisions. The fact that many patients prefer to give families leeway in decision making suggests that we too should focus our efforts on supporting the family in their decision making process. Secondly, because we know it is generally not possible to guess the patient's preferences, we should modify our approach to focus on respecting the patient, which we can continue to do in all cases.

In this new approach, we would conceptualize the problem as one of a family in crisis, needing to make a decision that reflected their knowledge of the patient, but with consideration of the context of the patient's current illness. This approach does not preclude the use of substituted judgment in some circumstances. Mostly, those will be situations where the patient clearly stated a preference.

### HETEROGENEITY OF PREFERENCES AND DECISION MAKING

Over the last two decades, we have learned much about the ways doctors and patients approach difficult decisions about providing or foregoing life-sustaining treatment. One lesson we've learned is that there is no single approach that works for everyone. Some individuals clearly value control and autonomy. Such individuals should be encouraged to leave specific instructions about their future care through a living will. To the extent that it is specific and applicable to the circumstances of a dilemma, we should regard this advance directive as a genuine expression of their autonomous wishes.

Given the data on its inherent flaws and its apparent inconsistency with the very principle of autonomy that it was designed to embody, it is time to let go of substituted judgment as the predominant model of decision making for the seriously ill. Doing so may help guide clinicians and loved ones to an approach that focuses on what we can genuinely know about another person's values, preferences, and interests.

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