Substituted Interests and Best Judgments: An Integrated Model of Surrogate Decision Making

Daniel P. Sulmasy; Lois Snyder


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Making decisions on behalf of patients without decision-making capacity remains challenging, especially at the end of life. Under the current US model, formal written or oral directives expressing patient wishes for future care are preferred. Lack of capacity or the patient’s preferences are unknown, a decision should be made in the patient’s best interests. This hierarchical model of separate standards, however, does not always reflect clinical reality or the interests of patients and families. In this commentary, we propose an alternative approach: the substituted interests model.

Decision making under the substituted interests model would be individualized and patient-centered and combine universal principles with empirical evidence about what individuals value and how they make decisions. This model emphasizes authenticity (i.e., a decision true to who the person really is) rather than the autonomy the patient cannot exercise,1 asking surrogates to provide substituted judgments, choosing what the patient would have chosen. If the patient never had capacity or the patient’s preferences are unknown, a decision should be made in the patient’s best interests. This hierarchical model of separate standards, however, does not always reflect clinical reality or the interests of patients and families. In this commentary, we propose an alternative approach: the substituted interests model.

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Substituted Interests Model

The substituted interests model integrates the currently separate standards into a contextualized process, unique to each patient, yet universal in its ethic. Rather than interpreting a text or making a substituted judgment about what the patient might have wanted in imperfectly foreseen circumstances, the surrogate is asked to apply the patient’s authentic values and real interests, including the patient’s known preferences. The key question under best interests is, “What do you think is best for your mother?” Under substituted judgment it is, “What would your mother choose if she could tell us?” The substituted interests model says, “Tell us about your mother.” A good surrogate can articulate the patient’s authentic values by describing the patient’s loves, beliefs, and fundamental moral commitments rather than just specific preferences (Table). Surrogates, ideally formally designated, know the patient as a person even if they do not know his or her precise wishes. This is what they substitute for the patient.

Author Interview available at www.jama.com.

How Should Decisions Be Made?

Decision making should honor the wide variability in patient beliefs about how decisions ought to be made. Some value autonomy highly and have detailed directives; others defer decisional authority to loved ones because they value relationships or cultural norms. Most patients prefer decisions using both their own preferences and the judgments of loved ones and physicians about what would be best for them.2 The substituted interests model provides for this individualized decision making (Table) and differs from other models as follows:

1. The hierarchical model emphasizes information and the intellectual process of decision making. Surrogates experience enormous stress,3 however, and the substituted interests model highlights empathy for the surrogate, not just a menu of options.

2. The hierarchical model emphasizes patient preferences, either in treatment directives or by substituted judgments. Nevertheless, only 5% to 25% of patients have advance directives.4 Treatment directives are often vague, inflexible, ignored, or not available.3 Most patients cannot anticipate all possible future circumstances and preferences may change in actual illness. Surrogates correctly predict patient wishes only about two-thirds of the time5; substituted judgment can be insensitive to familial and cultural values, and most patients do not want strict substituted judgments.6 Under the substituted interests model, clinicians would still elicit from the surrogate specific preferences but they also have knowledge of the patient’s values, commitments, and relationships, including the patient’s beliefs about how decisions ought to be made and by whom.

3. Clinicians describe the patient’s clinical situation and prognosis objectively in all models, but under the substituted interests model, decision making is shared with, rather than delegated to, the surrogate.

4. Patients make decisions in light of interpersonal relationships and cultural, religious, and other commitments. Patient interests also depend on the patient’s condition, of which the physician has expert knowledge. Under substituted interests model, the clinician draws on expertise and clinical experience to help the surrogate define the patient’s individualized interests, as a particular person in particular clinical circumstances.

5. Delegating decisions to surrogates leaves families less satisfied7 and more distressed8 than when they receive a clinical recommendation. Under the substituted interests model, after

Author Affiliations: Department of Medicine and Divinity School, University of Chicago, Chicago, Illinois (Dr Sulmasy); Center for Ethics and Professionalism, American College of Physicians, Philadelphia, Pennsylvania (Ms Snyder).

Corresponding Author: Daniel P. Sulmasy, MD, PhD, the Department of Medicine and Divinity School, MacLean Center for Clinical Medical Ethics, University of Chicago, MC 6098, 5841 S Maryland Ave, Chicago, IL 60637 (d.sulmasy@uchicago.edu).
reviewing options, the clinician recommends the course of action that best seems to serve the patient as a unique person.

6. When family members are asked to decide what they think is in the patient’s best interests, this often is not what surrogates would want for themselves. The substituted interests model guides surrogates to decide according to the individual interests of the patient, based on the patient’s values. This model respects the complex way in which surrogates actually make decisions, emphasizing the patient’s underlying values rather than potentially unknowable preferences. Under the substituted interests model, the clinician and the surrogate jointly judge what advances the individualized good of the patient in particular clinical circumstances, based on the patient’s values.

Role of Documents

Documents still have a large role. Under the substituted interests model, an advance directive serves as a guide, providing critical information but also stating whether patients intend their preferences to be followed strictly or loosely and who should be involved in making decisions. Above all, encouraging discussions with loved ones about the process of decision making becomes central to advance care planning.

Possible Objections

One concern is that the substituted interests model might reintroduce paternalism, but the authentic values of the patient remain primary and ultimate decisional authority still rests with the surrogate, not the physician. Surrogates do not shoulder all the burden either, given shared decision making and the incorporation of a physician recommendation. The stepwise and integrated process shown in the Table is designed to move discussion from surrogate needs and role to the values of the patient, to concrete clinical information and treatment goals, to the physician’s recommendation, and to a best judgment based on the individual interests of the patient. This teachable model truly respects patients as persons. The open-ended questions may appear time consuming, but failing to attend to the needs of surrogates and the underlying values of the patient may lead to greater conflict later. Finally, while some might already use this approach in practice, it has not been formally described and differs from standardly recommended models.

Conclusion

The substituted interests model reframes surrogate decision making as an approach that promotes the patient as a unique person, in the context of his or her relationships, applying the patient’s authentic values, wishes, and real interests, as best they can be known. Whether the model better serves patient values and alleviates unnecessary surrogate burdens will need to be studied. However, this model seems to respect patient rights and to serve each patient’s unique cultural, spiritual, familial, psychological, and clinical circumstances—what clinicians want to do for all patients, those who can speak for themselves and those who cannot.

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REFERENCES


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