

Substituted Interests and Best Judgments: Re-thinking Surrogate Decision Making

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

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COMMENTARY

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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. Lacking that, surrogates are instructed 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.

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. Now-

The Standard, Tripartite, Hierarchical View

Written or oral directive



Substituted Judgment



Best Interests

Talk Outline

- Origins of this model
- How this model fails to meet needs of patients and families
- Advantages of a new model: the Substituted Interests Model

Oral or Written Directives

- 1970s – The Living Will
- Problems:
 - Too vague (“no extraordinary means”)
 - Too specific (“CPR but no countershock”)
 - Texts to be interpreted
 - Only apply to the terminally ill
 - Most people never execute one
 - Fail to follow patients across care sites
 - Often ignored anyway
 - How valid are these hypothetical wishes to actual patient situation?

Oral or Written Directives

- Most bioethicists prefer Proxy over LW
- Why do we keep trying to “fix” this paradigm?
 - POLST

Substituted Judgment

- Make a decision based on what the patient would have wanted were the patient able to speak

Substituted Judgment: Origins

- 19th century estate cases – UK and US
 - *Ex parte Whitbred, a Lunatic*, 2 Mer. Rep. 99 (1816)
 - *In re Willoughby, a Lunatic*, 11 Paige 257 (N.Y. 1844)
- Kidney donors
 - *Strunk v. Strunk*, 445 S.W. 2d 245 (1969)
 - *Lausier v. Pescinski* 67 Wisc. 2d. 4, 226, N.W. 2d. 180 (1975)
- All persons lacking capacity
 - Robertson JA. “Organ Donations by Incompetents and the Substituted Judgment Doctrine” *Columbia Law Review* 1976;76:48-78

Substituted Judgment: US Legislative & Ethical Implementation

- President's Commission, 1983
- Brock and Buchanan "Deciding for Others" 1986
- Advance Directive Legislation
- Now in every standard bioethics textbook

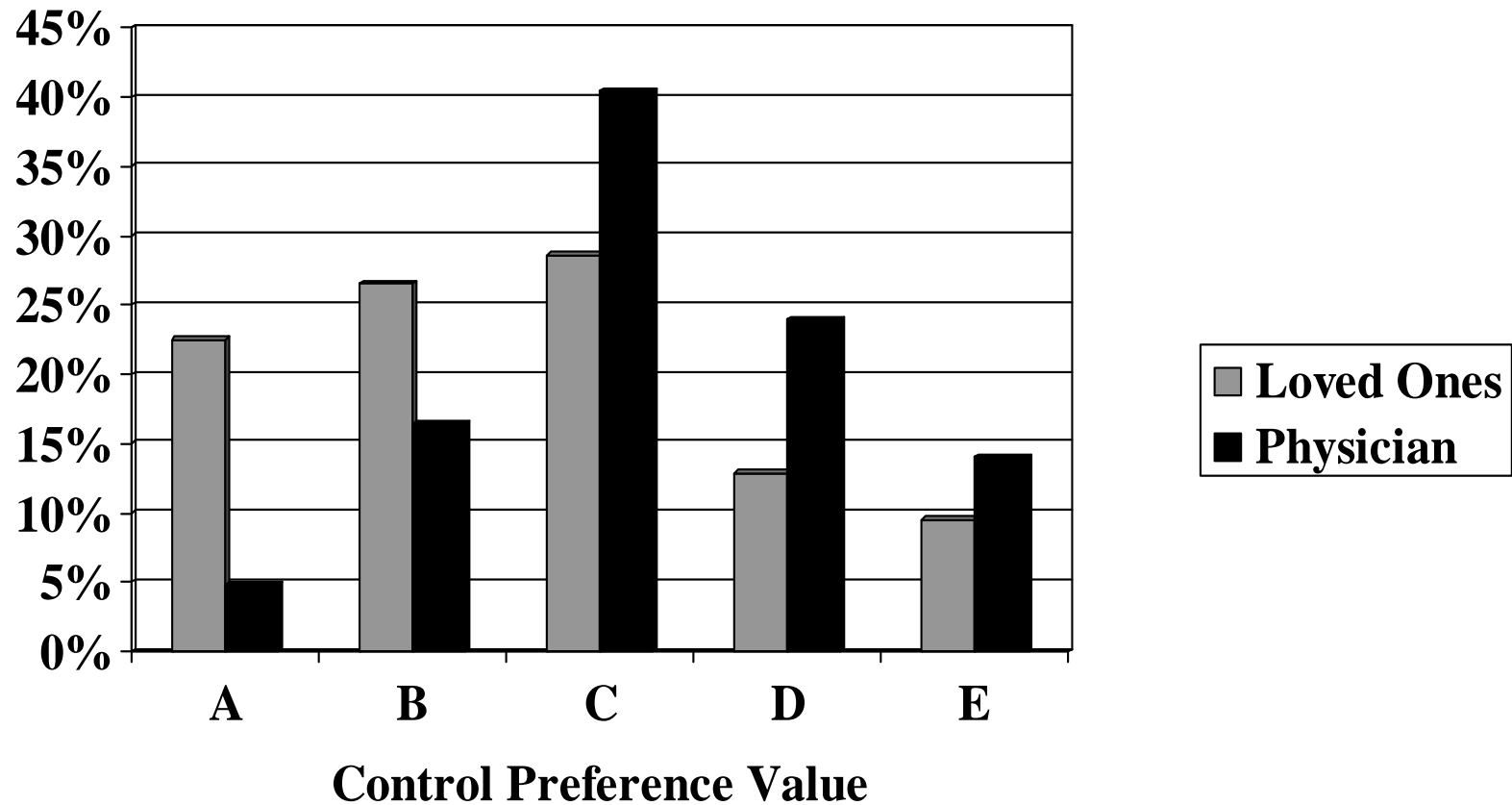
Problems with Substituted Judgment

- Surrogates are not very good at it: 68% accuracy
 - Shallowitz et al *Arch Intern Med* 2006
- Interventions don't improve
 - Ditto et al, *Arch Intern Med* 2001
- Most patients don't want a pure substituted judgment
 - Seghal et al *JAMA* 1992
 - Terry et al *J Clin Ethics* 1999
 - Hawkins et al *Gerontologist* 2005

Do patients want substituted judgments?

- Slight majority prefer surrogate over “perfect” living will
 - Terry et al. J Clin Eth
- Patients would give surrogates flexibility
 - Seghal, et al. JAMA

Figure 2. Baseline distribution of Decision Control Preferences of terminally ill patients in the event of decisional incapacity, with respect to loved ones and with respect to physicians. A = most independent, E = most reliant. Control preferences with respect to physicians are more reliant, $P < .001$.



Surrogate stress

- High scores on “Impact of Events Scale”
 - Tilden et al *Nursing Research* 2001
 - Sulmasy et al *JGIM* 2006
- Qualitative studies
 - Vig et al *JGIM* 2007
 - Braun et al *JGIM* 2008
 - Handy et al *J Pall Support Care* 2008
- Talking helps
 - Tilden (2001), Vig (2007), Handy (2008)

Critique: not sensitive to familial and cultural contexts

- Families

- Levine and Zuckerman *Ann Intern Med* 1999

- Cultures

- Blackhall et al *JAMA* 1995

Theoretical critiques

- The value of freedom is its exercise, not its outcomes
 - Freedman, *J Med Phil* 1978
- “Atomistic” notion of persons
 - High, *Hastings Cent Rep* 1994
 - Nelson & Nelson, *Hastings Cent Rep* 1994
- Logic and metaphysics
 - Wirenga, *J Med Phil* 1993
 - Nagasawa, *Bioethics* 2008

Best Interests

- Courts in 1960s and 70s
 - Only “objective” standard
 - Treatment rarely stopped
- Critiqued as “paternalistic”
 - Make your own subjective judgment for the patient
 - What surrogates say is in patient’s best interests is not what they want for themselves (Fagerlin et al *Health Psychol* 2001)
- Ignores knowledge surrogates might have about patients even if they do not know their exact preferences

Several corrective proposals

- “Blended” models
- “Narrative” models
- Revised “best interests”
- Substituted judgment—flawed, but nothing better?

An Alternative: The Substituted Interests Model

- Individualized and patient-centered
- Authenticity, not autonomy
- Substituted interests
- Best judgments
- Documents: guidelines, not recipes

Substituted Interests

Choose what you judge would best promote the good of the patient as a unique person, in the context of his or her relationships, applying your knowledge of the patient's authentic values, expressed wishes, and real interests, as best they can be known, to the current clinical circumstances.

Primary Clinical Questions

- Oral or Written Directive
 - Best Interests
 - Substituted Judgment
 - Substituted Interests
- What does the directive instruct us to do?
 - What do you think is best for your mother?
 - What do you think your mother would have wanted were she able to speak to us?
 - It must be very hard to see your mother so sick. Tell us about her.

Who decides?

- Surrogate retains final authority
 - Unless there is a gross conflict or surrogate lacks capacity
- Ideally = legally designated proxy
 - Can write down a name
- Failing this, a legal hierarchy
 - Guardian
 - Spouse
 - Adult child
 - Parent
 - Other relative or friend

How should decisions be made?

- Patients who value autonomy highly
 - Living will, or
 - Strict instructions for surrogate
- Most want some family input
- Some leave up to the family completely
- Always in the context of family
- Physician provides a recommendation
- Shared decision making

The use of documents

- Durable Power of Attorney for Health Care (Proxy) preferred
- May include specification of particular preferences (combination form)
- Ought to include instructions on how closely preferences should be followed and role of surrogates and family
- Always talk!
- Living wills (+/- a “Values History”) for those with no one to speak for them.

Substituted Interests: Step by Step

1. Empathic connection
2. Authentic values
3. Clinical data
4. Substituted Interests
5. Clinical judgment
6. Best judgment for the patient

1. Empathic Connection

- “It must be very difficult to see your loved one so sick.”

2. Authentic Values

- Tell us about your loved one.
- Has anyone else in the family ever experienced a situation like this?

3. Clinical Data

- All of this discussion will help us make the best decision for your loved one.
- Here is what is wrong.
- This is what is likely to happen.

4. Substituted Interests

- Knowing your loved one, what do you think would be most important for him or her right now?
- What do you think are your loved one's real interests right now? Avoiding pain? Having family visit?

5. Clinical Judgment

- Here's what could be done.
- Here's what we would recommend, based on what we know and what you've said about your loved one.

6. Best judgment

- Knowing your loved one, does our recommendation seem right for him/her?
- Do you think another plan would be better, given his/her values, preferences, and relationships?

Substituted Interests:
A New (Old) Model of
Surrogate Decision Making



Key References

- Sulmasy DP, Snyder L. Substituted interests and best judgments: an integrated model of surrogate decision making. *JAMA* 2010;304:1946-7
- Sulmasy DP. Research in medical ethics: scholarship on “substituted judgment.” In: Sugarman J, Sulmasy DP, eds. *Methods in Medical Ethics*, 2nd ed. Washington, DC: Georgetown University Press, 2010.

Possible Objections

- Neo-paternalism
- Too complex
- Too time-consuming
- This isn't new
- SIM is centered on *patient* interests; surrogate still has last word
- Oversimplification hasn't worked; this *is* complex
- Alternative is more complications and time spent later
- Not previously articulated as a model; not what law & bioethics now standardly counsel

Authentic Values

- Patient's fundamental moral commitments
- Who the patient loves
- What the patient stands for
- How the patient has acted in the world
- Specific preferences
 - Unless otherwise specified by the patient, these should serve as evidence of the patient's authentic values, not as an algorithm

Real Interests

- Given the patient's authentic values
- Given the patient's unique characteristics
 - Tolerance for pain
 - Family circumstances
- Given the clinical circumstances
- Given the prognosis
- What would seem to be the real interests of this patient as a unique person in this situation?