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# **On proxy decision making, substituted judgment, best interests and respect for autonomy**

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# Respecting autonomy (in the US)

## **Right to refuse medical treatment:**

*Legal and Ethical Considerations in  
End-of-life Care of Mentally Incompetent Patients*

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- “Law sides with patients to oppose the arbitrary use of power whether by physicians or the government; the rubric is patient rights. This is why American law, not philosophy or medicine, is primarily responsible for the agenda, development and current state of American bioethics.”

(G. J. Annas, *Standard of Care*, 1993)

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## Proxy: Family members make substituted judgment for incompetent patients (in the US)

- Two decades of court cases and public debates in the US (from the 1970s) on withholding medical treatment were anchored on constitutional right to privacy, and on empowering family members or close friends to take up the **health care proxy** role.
  - After the case of Nancy Cruzan (1990) every state has passed **durable power of attorney laws** to cover health care proxy naming. Some states passed statutes to authorize specific family members to make decisions for their loved ones.
  - Even without statutory proxy, the Supreme Court has in some cases stated that family members are best qualified to make **substituted judgments** for incompetent patients.
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# In the UK

- The traditional focus was on protecting incompetent patient's **best interests**. The role of doctors is more prominent.
  - *Mental Capacity Act 2005* has expanded the concept of 'best interests' to include finding out the patient's view as far as possible.
  - It also widened the remit of the powers of attorney (PoA) to cover personal care and treatment (at the same time replaced the term 'Enduring PoA' with 'Lasting PoA')  
(M. Stauch, K. Wheat. Text, Cases and Materials on Medical Law and Ethics 2012)
  - Guardianship order: Allows appointed person (usually family member) to make decisions about the care and finances of the MIP
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# Substituted judgment

- In the UK legal framework, substituted judgment is not the underpinning concept but the *Mental Capacity Act 2005* implies the need to consider what the patient would have wanted
- Although taught and used in the US, the concept of substituted judgment has also been subject to debate:

“...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.”

(A.M. Torke et al. Substituted Judgment: The Limitations of Autonomy in Surrogate Decision Making. *J Gen Intern Med.* 2008 Sep; 23(9): 1514–1517.)

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## **Beyond autonomy: diversifying end-of-life decision-making approaches to serve patients and families.**

Review article

Winzelberg GS, et al. J Am Geriatr Soc. 2005.

### **Authors**

[Winzelberg GS](#)<sup>1</sup>, [Hanson LC](#), [Tulsky JA](#).

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### **Citation**

J Am Geriatr Soc. 2005 Jun;53(6):1046-50.

## **"Thinking about it for somebody else": Alzheimer's disease research and proxy decision makers' translation of ethical principles into practice.**

Dunn LB, et al. Am J Geriatr Psychiatry. 2013.

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- Best interests standard lacks a clear definition, although in practice it may incorporate a surrogate's perceptions of the patient's quality of life
- Advance directives and surrogate decision-makers are valued as extensions of the patient's autonomy (but...)
- Patients (chronically ill and cancer patients) have heterogeneous attitudes towards autonomy as a decision-making priority
- Patients may value autonomy but focus on sense of control and "being treated as a whole person"
- Patients may also desire to avoid burdening loved-ones

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Advocated: Customize communication approaches to serve diverse patient/family priorities (for both capable and incapacitated patients)

- For incapacitated patients, identify family who prefer to use a strict substituted judgment decision making standard
- For other families, present substituted judgment as one of the factors to consider.
- Discuss decision-making factors including patient's preferences, perceived quality of life, safety, the family's interests such as caregiver burden
- Present decisions as a shared responsibility between physician and family
- Make treatment recommendations after discussion and give family permission to choose palliative care

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- Ethical guidelines suggest that, when enrolling patients with dementia in research, substituted judgment should be made by the proxy, if unable to do so, proxies are asked to decide on the basis of the patient's best interests.
- This study: examines explicitly whether and to what degree proxies differentiate between these two approaches. In the study, substituted judgment was framed as honouring the patient's wishes and values; best interests was described as a perceived duty to maintain quality of life and avoid burdens or risks

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- The hypothesis: “That proxies would more strongly endorse the use of a best interests standard, that proxies would describe a desire to protect the patient’s quality of life, and that “best interests” would trump “substituted judgment” when research was viewed as potentially risky.”
- Proxies were randomly assigned to a mock informed consent process for one of four hypothetical protocols with different levels of described risk and potential benefit.
- Their understanding of the protocol was assessed by a structured tool. They were then interviewed in depth (scaled items plus open-ended questions).
- Asked to rate “best interests” and “substituted judgment” , and answer a force-choice item, then probe their basis for rating.

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- “Substituted judgment” – 67.5% agreed or strongly agreed
- “Best interests” – 77.5% agreed or strongly agreed
- “Forced choice” – 57.5% endorsed using primarily best interests; 42.5% primarily substituted judgment
- Found: Tensions exist between abstract ethical principles regarding decision-making standards and their translation into research decisions

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- An unexpected theme: proxies may attempt to discern their loved one's current versus premorbid preferences:
- “If the proxy believed that the patient currently would prefer not to participate, they acknowledged a certain point beyond which they would not be willing to force the patient to participate.”

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# Thoughts on Hong Kong

- Practice and guidelines are broadly along UK rather than US framework
  - For incapacitated patients, treasures consensus building between physicians and family
  - Best interests standard widely understood? Narrow concept or following the UK broader concept since Mental Capacity Act 2005?
  - Respect for autonomy - “What patient would wish” – how may it be reflected in practice?
  - Lasting power of attorney and advance directives
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Thank you for your attention

