

Autonomous Decisions in Intensive Care: Obstacles

Jason Phua

Division of Respiratory and Critical Care Medicine

National University Hospital

National University Health System

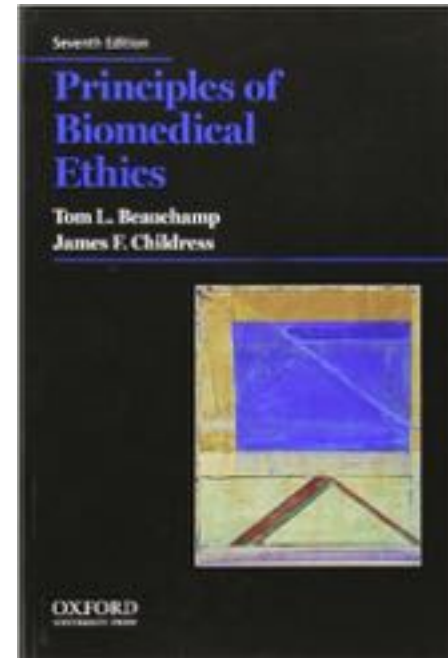
Singapore

jason_phua@nuhs.edu.sg



autos = self

nomos = rule, governance, or law



Personal rule of the self that is
free from both **controlling interferences** and
from **personal limitations** that prevent meaningful choice,
such as inadequate understanding

Personal limitations

Can't make decisions: too unwell



Truog et al, Crit Care Med 2008
Cassell et al, Ann Intern Med 2001

Personal limitations

Can't make decision: too medical



Portanova et al, Resuscitation 2015

Adams and Snedden, J Am Osteopath Assoc 2006

Personal limitations

Can make decision: but refuses

Table 1. Control Preferences Scale^{16,17}

Response Choice	Statement
A	I prefer to make the final selection about which treatment I will receive
B	I prefer to make the final selection of my treatment after seriously considering my doctor's opinion
C	I prefer that my doctor and I share responsibility for deciding which treatment is best for me
D	I prefer that my doctor make the final decision about which treatment, but seriously considers my opinion
E	I prefer to leave all decisions regarding treatment to my doctor

NOTE. The first two statements (A and B) are considered reflective of an active role, the third statement (C) indicates preference for a collaborative role, and the last two statements (D and E) reflect a passive role.

Table 5. Physician Perception Versus Patient Preference for Decision Control

Patient Preference	Physician Perception of Patient Preference					Total
	A	B	C	D	E	
A	0*	0	0	1	0	1
B	1	2*	7	3	0	13
C	0	4	3*	5	3	15
D	0	0	6	6*	4	16
E	0	3	4	5	4*	16
Total	1	9	20	20	11	61

NOTE. Assessed by Control Preference Scale.^{16,17}

*Concordance exists between patient preference and physician perception.

Controlling interferences

Family influence

Systematic Review: Individuals' Goals for Surrogate Decision-Making

Brenna Kelly, JD, MPH,* Annette Rid, MD,^{†‡} and David Wendler, PhD[§]

OBJECTIVES: To determine to what extent current practice promotes the goals of individuals who did not designate a surrogate while competent with respect to decision-making during periods of decisional incapacity.

DESIGN: Systematic literature search for studies published in English and listed in PubMed, Scopus, Embase, CINAHL, or PsycINFO. Studies were eligible if they provided quantitative or qualitative empirical data on how adults want treatment decisions to be made for them during periods of incapacity.

SETTING: Primarily United States, with six other countries.

PARTICIPANTS: Fourteen qualitative articles, representing 11 distinct data sets, and 26 quantitative articles, representing 25 distinct data sets, providing data on the views of 22,828 individuals, met the inclusion criteria. Most of the respondents were elderly or seriously ill.

MEASUREMENTS: Quantitative surveys and qualitative interview studies assessing individuals' goals.

RESULTS: The majority wanted close family members to act as their surrogate. The most common reason for preferring family members was the belief that they know which treatments the patient would want. Individuals also wanted to reduce the burden on their families. There was significant variation in the extent to which respondents wanted their surrogates to have leeway when making treatment decisions.

CONCLUSION: Individuals have three primary goals with respect to making treatment decisions for them during periods of incapacity: involve their family, treat them consistently with their own treatment preferences, and reduce the burden on their family. Unfortunately, prior systematic reviews have found that family members often are not able to determine which treatment patients want, and family members frequently experience substantial distress when

acting as surrogates. These findings suggest that current practice frequently fails to promote individuals' primary goals for treatment decision-making. Future research should evaluate ways to better promote individuals' goals. In the meantime, clinicians should be aware of these findings and should encourage patients to document their own goals, including their treatment preferences and their preferences regarding how they want decisions to be made for them during periods of decisional incapacity. *J Am Geriatr Soc* 60:884-895, 2012.

Key words: surrogate; end of life; decision-making; incapacity; goals; preferences; values

Respect for autonomy implies that individuals should be allowed to make their own treatment decisions, typically in consultation with a clinician. Yet many people, including the majority of those at the end of life, are not able to make decisions.¹⁻³ Moreover, the majority of individuals do not complete an advance directive or otherwise leave clear instructions for how they want to be treated during periods of decisional incapacity.⁴

Designated surrogates make decisions for incapacitated individuals who completed a durable power of attorney while competent. For incapacitated individuals who did not designate a surrogate while competent, the next of kin makes treatment decisions. Surrogates, whether patient designated or next of kin, are instructed to make decisions based on the substituted judgment standard, making the treatment decision they think the individual would have made if he or she were capable.^{5,6} Proponents argue that this approach extends individual autonomy by allowing individuals' preferences and values to guide how they are treated, even when they are not able to make their own decisions.

No systematic analyses have attempted to identify individuals' goals with respect to treatment decision-making during periods of incapacity. As a result, it is unclear to what extent current practice promotes individuals' goals. In the absence of an advance directive, how do individuals want treatment decisions to be made for them? Does current practice of relying on the next of kin, and

Patients' goals for families:

- 1) Help!
- 2) Get it right!
- 3) No stress!

From the ¹University of Michigan Law School, Ann Arbor, Michigan; ²Institute of Biomedical Ethics, University of Zurich, Zurich, Switzerland; and ³Department of Bioethics, National Institutes of Health Clinical Center, Bethesda, Maryland.

Address correspondence to David Wendler, Department of Bioethics, NIH Clinical Center, Building 10, Room 1C118, Bethesda, MD 20892. E-mail: dwendler@nih.gov

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Kelly et al, JAGS 2012

Controlling interferences

Family influence

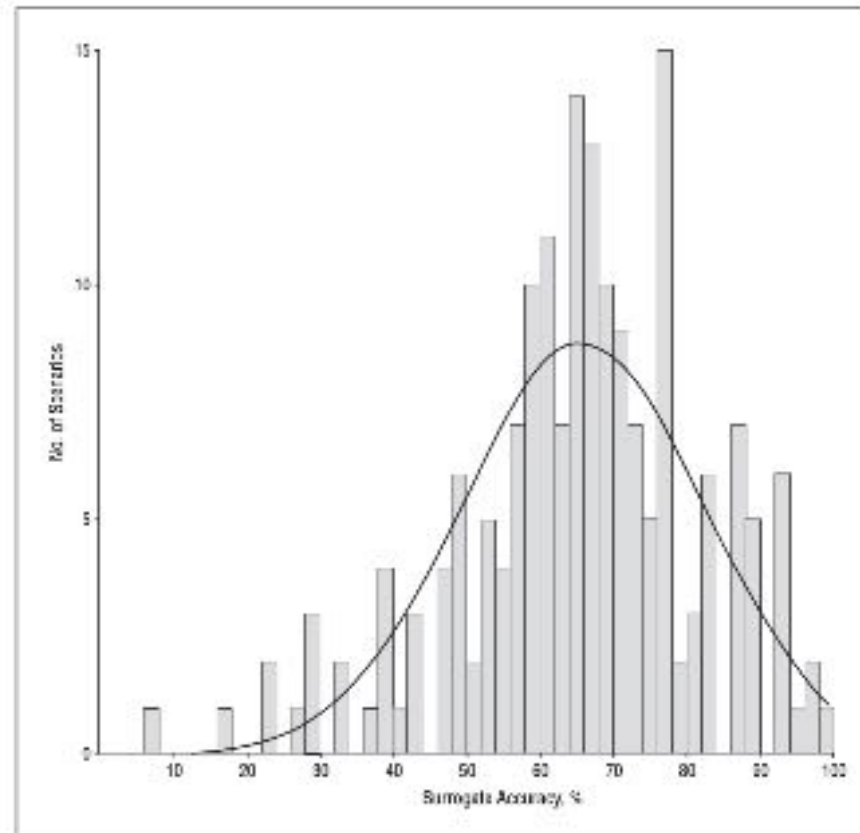


Figure 2. Distribution of surrogate accuracy in individual scenarios. Each column represents the number of scenarios in which the given percentage of surrogates accurately predicted their patient's treatment preference. The histogram includes 151 scenarios, 2595 surrogate-patient pairs, and 19 526 total paired responses. Adjusted overall accuracy of surrogates, based on meta-analysis, is 68% (95% credible interval, 63-72).

Controlling interferences

Family influence



Mr Manisaran Kanniah, 46, has motor neuron disease, a typically fatal illness that sees patients dying within two to five years. It was to get insight into the situation of patients like Mr Kanniah, as seen from the doctor's perspective, that led Dr Jaciela Tan (left) and Professor Jacqueline Chin to conduct the study *What Doctors Say About Care Of The Dying*. **MORE REPORTS: PRIME PAGE A6, HOME PAGES B2-3.** ST PHOTO: ASHLEIGH SIM

Patients' families here 'play big role in medical decisions of the dying'

BY SALMA KHALIK
HEALTH CORRESPONDENT

IN THE first survey of its kind here, researchers have found that family members tend to take over the decision-making when it comes to the care and treatment of people who are dying.

Unlike in Western developed coun-

tries, where patient autonomy rules, it is the family who has the most say here on matters like whether the patient ought to be told that he is dying, and the sort of treatment he gets.

This situation can lead to "tensions between doctors and families of patients", said the researchers.

This is because under the law, doc-

tors are in fact answerable only to the patient and must protect his confidentiality. But they often find they have to work hard on family members to be allowed to talk to the patient truthfully.

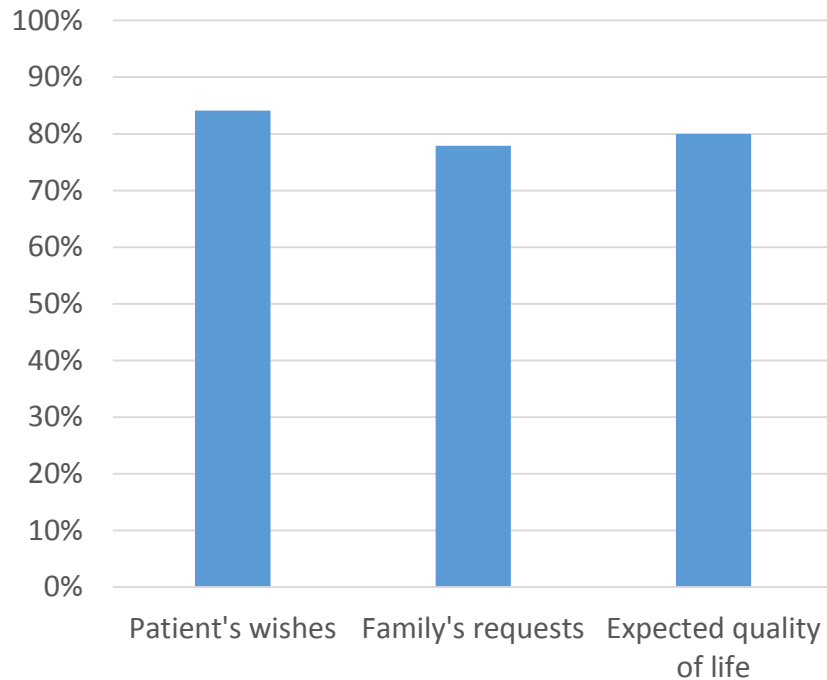
This clash of what the law and ethical codes say versus the culture here raises

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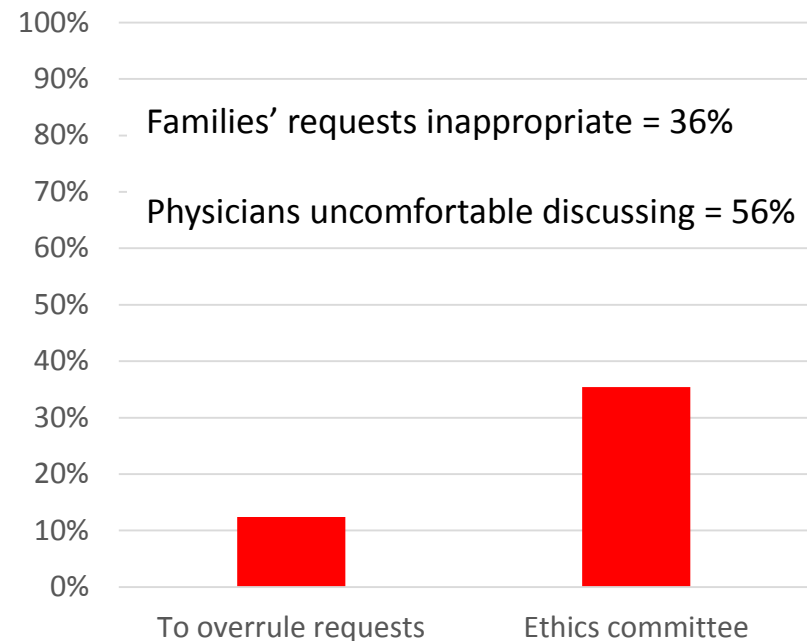
Controlling interferences

Family influence

Factors to consider for limiting life-sustaining treatment



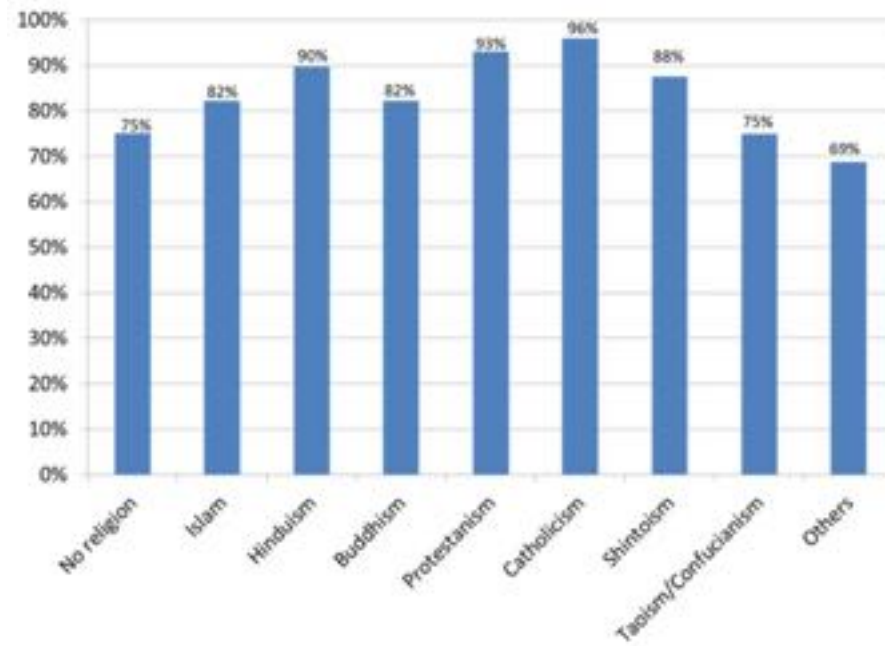
Policies



Controlling interferences

Physician preference

Physicians who would implement DNR orders
in hypoxic-ischemic encephalopathy



Controlling interferences

Physician preference



A large, dark, textured boulder is positioned in the center of a paved road with two yellow lines. The road leads towards a dark, wooded area in the background. The word "Obstacles" is written in white, sans-serif font across the front of the boulder.

Obstacles

Personal limitations:

Too sick

Too medical

Refuses to decide

Interferences:

Family

Physician

It's never too early to talk

ANNALS OF MEDICINE | AUGUST 2, 2010 ISSUE

LETTING GO

What should medicine do when it can't save your life?

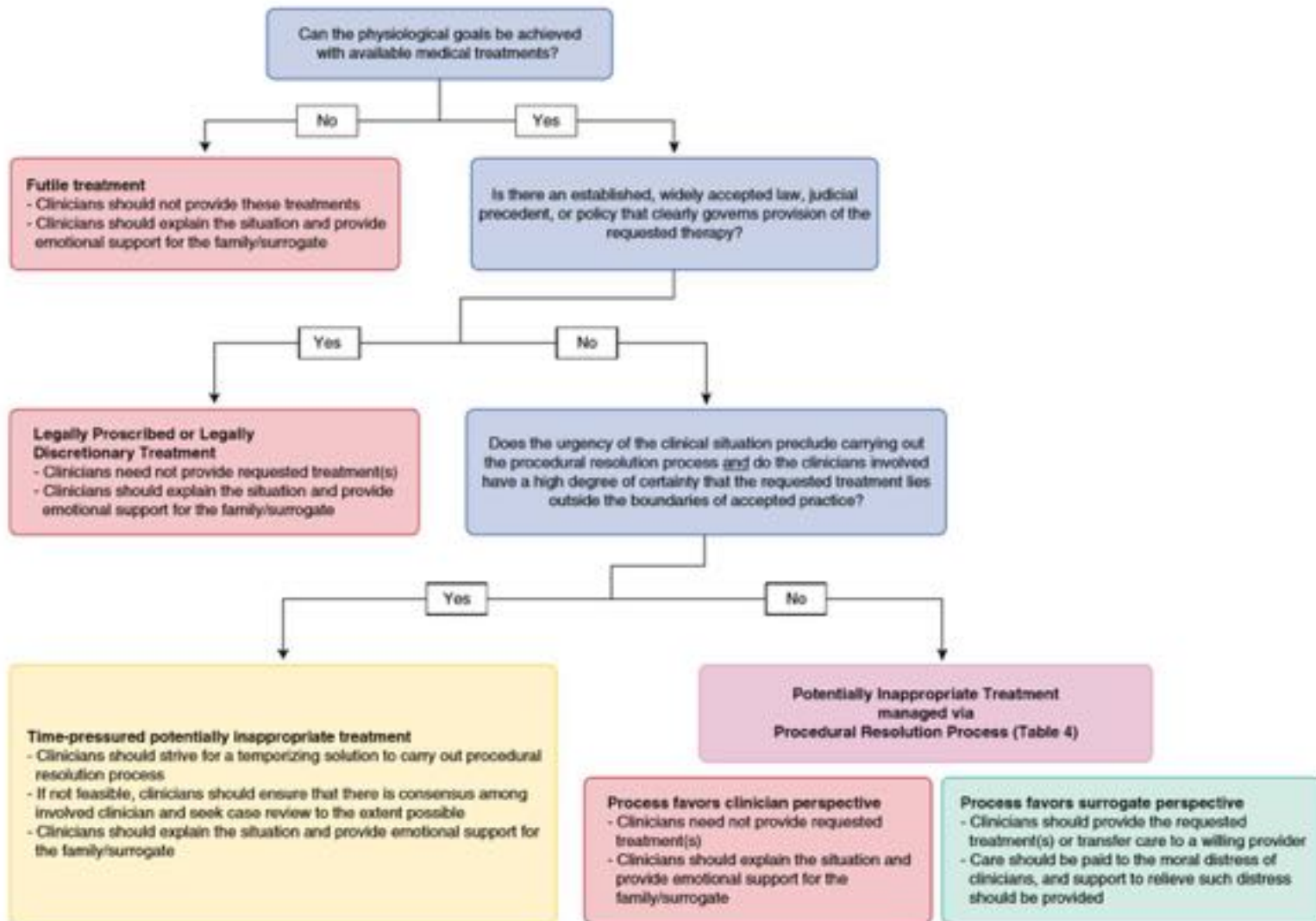
BY ATUL GAWANDE



Gawande, The New Yorker 2010

Deciding not to decide is a decision







**KEEP
CALM
YOU'RE THE
DOCTOR
NOW**

A vibrant night scene of a city skyline, likely Singapore, with fireworks exploding in the sky. The fireworks are in shades of blue, red, and orange, and their reflections are visible on the water in the foreground. The city skyline is illuminated with various lights, and the water reflects the lights and fireworks. The text "Thank you" is overlaid on the right side of the image.

Thank you

jason_phua@nuhs.edu.sg