

# ELLIS ETHICS COMMITTEE: TRENDS, SHARED AUTONOMY, AND A NURSING PERSPECTIVE

Ellis Medicine Department of Internal Medicine

Grand Rounds

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My patient's family  
is making him  
make decisions that  
aren't what he wants !

Mr. S 60-year-old man with DM, stage IV CKD, and CHF. His 2-month hospitalization complicated by

- HCAP, AF, AKI requiring dialysis
- Recurrent trips to ICU, including intubation & mechanical ventilation
- Extubated four days ago
- He tells his nurse that he would not accept reintubation.
- DNR/DNI ordered
- The next day the patient's daughter persuades him to agree to a "full code"
- When only with nurse Mr. S says he is "sick of this" and "just wants to go home and die."
- However, whenever his daughter is present, he expresses willingness to accept life-sustaining treatments.
- Staff are distressed and feel that his daughter is bullying him into accepting medical care that he doesn't want.

# Take Home Points

Autonomy may be  
“our’s” rather than “mine”

“I’m tired of this” ... “Don’t give up”  
think *emotions*, not decisions

Lean on me .... Patients frequently  
share their woes with nurses  
so as to not trouble their families

Childers, J.W. and R.A. Arnold.

***“She’s Not Ready to Give Up Yet!”: When a Family Member Overrides the Patient’s Medical Decisions”***

Journal of Pain Symptom Management.  
2021;62:657–661.

M Hedlin.

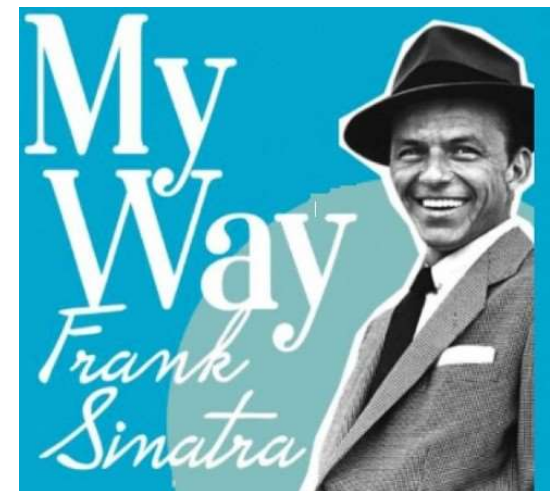
***“The Web We Weave”***

New England Journal of Medicine. 2021:  
385;23:2119-2121.

# Autonomy

Childress & Arnold, JPSM 2021

“Health care decisions should be based on an individual’s self-directed preferences, which are the main factors to be considered when making autonomous decisions”



....”there is no “me” without relationships—that one’s roles as a parent, spouse, and/ or member of a particular religious community are a key part of ourselves and necessarily factor into our choices.”

Childress & Arnold, JPSM 2021

# The Golden Rule

That nature only is good  
when it shall not do unto  
another whatever is not good  
for it's own self.



Blessed is he who prefers his brother  
before himself.

What is hateful to  
you, do not do to  
your fellow man.  
That is the entire  
Law; all the rest is  
commentary.



Hurt not others with  
that which pains  
yourself.

This is the sum of duty:  
do naught to others that  
which if done to thee  
would cause pain.



No one of you is a believer  
until he desires for his  
brother what he desires for  
himself.

Do unto others as you  
would have them do  
unto you.



**Should doctors inform patients of metastatic cancer?  
Announce a terminal prognosis? Who should make life-  
support decisions?**

	Tell Diagnosis	Tell Prognosis	Patient Decides
European- Americans	87%	69%	65%
African- Americans	88%	63%	60%
Korean- Americans	47%	35%	28%
Mexican- Americans	65%	48%	41%

Blackhall, L.J. Ethnicity and Attitudes Toward Patient Autonomy. JAMA. 1995.

**“Relational autonomy** sees people as interconnected and interdependent, shaped by their culture, communities, and relationships with loved ones. It acknowledges that we achieve autonomy *with* others, that we can become who we truly are within our web of relationships rather than independently of it.”



M Hedlin NEJM 2021

“In medical training, we’re taught to respect autonomy, to take the patient’s wishes as the final word. But I wasn’t taught how to reconcile conflicting values, didn’t know how to help my patient weigh his wish to die peacefully against his desire to make a decision his family could accept.”

M Hedlin NEJM 2021

# Degrees of Autonomy of Intentional Actions

Fully  
Understood

Fully  
Ignorant

Completely  
Noncontrolled

Completely  
Controlled

Adapted from Faden RR, Beauchamp TL. A history and theory of informed consent. New York: Oxford University Press; 1986.

We should ask patients how they want to make decisions.

Do they want a loved one at their bedside, or do they prefer to discuss decisions with a clinician privately?  
Are there certain family members they trust more than others?

If the patient chooses to include others in decision making, the clinician should confer privately with the patient after the meeting to ensure that the patient's views have been adequately represented.

Explicitly defer to another

Explicitly state priority of values

Is the decision “in character or out of character” ...  
the decision and *the reasoning behind it* is consistent  
with other choices the patient has made

## Coercion ?

- Tactics ...controlling, intimidating, or using threats
- Badgering the patient
- Do this or else ... financial support, opportunity to see family
- Family member threatens to kill themselves

“Aside from more extreme concerns, however, our role as health professionals is not to alter a couple’s long-standing dynamics and decision-making processes”

Childress & Arnold, JPSM 2021

“Many people in your situation value their family’s well-being very highly and make decisions based on that. Is that true for you?”

“So I hear you saying that you feel tired of going through all this treatment, but your husband’s well being is also very important, so you have decided to continue treatments. Is that right?”

I’m wondering if what I’m hearing is that you really feel like you’re ready to stop all these treatments, no matter what your husband says.”



*“I just want to be done with this”*

*“You can’t give up now”*

*“I can’t lose you”*

Statements reflecting *emotion*, not necessarily a decision

Explore & support the patient & family’s grief

“Its a process, not an epiphany”

Stefanie Nemec, LMSW

“The model of autonomy I was taught expects discrete, consistent answers —decisions that express a person’s deeply held, steadfast values and preferences. But decision making is an evolving process: people continually incorporate new information, new experiences, and new perspectives to come to a more nuanced understanding of what they want.”

M Hedlin NEJM 2021

“ In many of these cases, the patient then expresses such preferences to the nurses and other clinical staff, because telling their loved ones would cause too much pain or bring up conflict they do not wish to face.”



Childress & Arnold, JPSM 2021