Ethics Committees Are Not Just for Hospitals: Advancing Person-Centered Care in Long-Term Care Facilities

ASBH (Oct. 21, 2018)
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I do have a disclosure

Question 1

Does Armando have capacity?
Key **threshold** question

Patient has capacity to make decision at hand

Patient decides **himself**

What is **“capacity”** 3

Able to **understand** significant benefits, risks and alternatives to proposed health care

Able to **make** a decision
Able to communicate a decision

2 famous case examples

Lane v. Candura (Mass. 1978)

77yo Rosaria Candura
Gangrenous right foot and leg
Refuse consent for amputation

Doc thinks stupid decision
But . . . Pt understands the diagnosis & consequences
So, she has capacity

DHS v. Northern (Tenn. 1978)
Mary Northern, 72yo
Gangrene both feet
Amputation required

Does not appreciate her condition
Believes her feet are black “because of soot or dirt.”

Armando
Capacity - Step 1

“I am not going to the hospital. I don’t care if I have gangrene.”

May appreciate diagnosis
“I have gangrene”

May appreciate need to treat
“My leg needs to be healed”
“God will heal my leg.”

Able to understand significant benefits, risks and alternatives to proposed health care

Able to make & communicate a decision

“Plus

“I am not going to the hospital”

“Armando understands that he may have lung cancer and tells the doctor and the social services designee in lucid moments . . .”

“I don’t want to have a lot of treatment or go to the hospital. I’m tired, and when my time is up, I am ready to go.”
All patients presumed to have capacity

Clinicians must rebut the presumption

No need to prove capacity

Must prove incapacity
Unclear that can be done

Armando
Capacity - Step 3

Even if really lacks capacity

Restore capacity if possible

Recap

Armando has capacity
Armando decides
What if Armando **really** lacks capacity?

Is this an emergency?

If yes →

Cannot use emergency exception if know patient would **object**

Proceed with **implied** consent
We already determined Armando lacks capacity to object.

Question 3

What if Armando really lacks capacity?

Not an emergency

Find a surrogate

No family identified by patient or in any of his records. Has one sister in Florida but does not want efforts made to find or contact her. Parents both dead. No children, never married. No close friends identified by patient as potential surrogates.”
That’s what Karl **thinks**

Diligent search for surrogates

Surrogates usually found for most **thought** to be unrepresented

Even if no surrogate, search may reveal **evidence** of patient’s values, preferences

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**POSITION STATEMENT**

**Making Treatment Decisions for Incapacitated Older Adults Without Advance Directives**

AGS Ethics Committee

**POSITION 2**

- It should not be assumed that the absence of traditional surrogates (next-of-kin) means the patient lacks an appropriate surrogate decision-maker. A nontraditional surrogate, such as a close friend, a live-in companion who is not married to the patient, a neighbor, a close member of the clergy, or others who know the patient well, may, in individual cases, be the appropriate surrogate. Health professionals should make a conscientious effort to identify such individuals.
What if you cannot find a surrogate?

Increasingly common situation

Patient needs treatment

BUT

No capacity

No surrogate
Patient **cannot** consent

Nobody else to consent

Various terms

“unrepresented”
“adult orphan”

Patient w/o proxy
Incapacitated & alone

Most prevalent
“unbefriended”
Incapacitated and Alone: Health Care Decision-Making for the Unbefriended Elderly

Naomi Karp and Erica Wood

American Bar Association Commission on Law and Aging
July 2003

Advocating for the Unbefriended Elderly
An Informational Brief

August 2010
Jessica E. Brill Ortiz, MPA

AGS Position Statement: Making Medical Treatment Decisions for Unbefriended Older Adults

AGS Geriatrics Healthcare Professionals
Leading Change. Improving Care for Older Adults.

Big problem

LTC estimates
Incapacitated and Alone: Health Care Decision-Making for the Unbefriended Elderly

Naomi Karp and Erica Wood

American Bar Association
Commission on Law and Aging
July 2003

3 - 4 %
U.S. nursing home population

> 56,000
USA

1.4 million

> 6700
CA

Growing problem
4 key factors

1

2

10,000,000 Boomers live alone

Outlived
Lost touch
Others, like Armando, “have” family members

But Armando does not want them
They do not want Armando
No **contact** (e.g. LGBT, homeless, criminal)

**Who decides?**

Cal. H&S 1418.8 (1992)

**IDT**

Interdisciplinary team
1. Physician
2. Registered professional nurse with responsibility for the resident
3. Other staff in disciplines as determined by resident's needs
4. Where practicable, a patient representative

IDT acts as surrogate

BUT

IDTs vary in effectiveness & fairness

Most states have no 1418.8 or any mechanism
What happens in those states?

1. Under-treatment

2. common responses

Reluctant to act without consent

Wait
Wait some more

Until emergency
(implied consent)

BUT

Longer period suffering
Increases risks

2014

Ethically “troublesome . . . waiting until . . . condition worsens into an emergency”
2
Over-treatment

Fear liability
Fear regulatory sanctions

Treat aggressively

BUT

Burdensome
Unwanted
"compromises . . . consideration of patient preferences or best interests"

Takeaway

No consent $\rightarrow$ Bad conduct

Need a consent mechanism

HEC
Law

An Act

HOUSE BILL 16-1101

BY REPRESENTATIVE(S) Young, Caotic, Lagal, Fields, Obaj, Kagan, Kraft-Tharp, Lountie, McCann, Mitch Bush, Plben, Peterson, Primavera, Rozenhol, Wyden, Salazar, Singer, Vigli, Hollingsworth, Danishon, Denver, Klingenschmitt, Movus,
also SENATOR(S) Lundberg, Aguilar, Crowder, Guitierrez, Heath, Hodge, Jaho, Kefalas, Kerr, Mortfield, Newell, Steadman, Todd.

Concerning medical decisions for unrepresented patients.

59th Legislature

AN ACT ALLLOWING FOR APPOINMENT OF PROXY DECISIONMAKERS FOR CERTAIN HOSPITALIZED PATIENTS: ESTABLISHING PROCEDURES FOR MAKING PROXY DECISIONMAKERS: ALLOWING HEALTH CARE PROVIDERS TO SERVE AS PROXY DECISIONMAKERS: PROVIDING FOR REVIEW BY MEDICAL ETHICS COMMITTEES: PROVIDING IMMUNITY: PROVIDING DEFINITIONS, AND PROVIDING AN
AGS Position Statement: Making Medical Treatment Decisions for Unbefriended Older Adults

Use of Institutional Committees
The best interest standard is typically applied only as a last resort when there is no advance directive available and a surrogate decision maker cannot be identified. According to the AGS, institutional committees, such as ethics committees, should require the synthesis of all available evidence about unbefriended older adults' treatment preferences.

Efficiency Fairness

Fair

Expert Neutral Careful

Too fair → too slow
Fast
Accessible
Quick
Convenient

Too fast →
too unfair

Goldilocks problem

Some mechanisms are too slow
Other mechanisms are **too fast**
Unrepresented patients in LTC should get the same respect

“highly vulnerable”
“most vulnerable”
“unimaginably helpless”

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