Unbefriended and Unrepresented: Better Medical Decision Making for Incapacitated Patients without Healthcare Surrogates

Thaddeus Mason Pope, JD, PhD
Mitchell Hamline School of Law

I have no conflicts

October 18-21

Four sections
1. Biographical sketch
2. Experiences 1933 to 1939
3. Events during the war
4. Fate - how died or survived

Any one of us might be unrepresented

Veil of ignorance
Cannot identify you
Try to contact your family, so they can guide treatment
If cannot
Try to identify you
Try talk to you - to ascertain what you want
If cannot
Use fair process to determine treatment
How well does CA law & policy measure up?

Roadmap

Decision making capacity

Making decisions when patient lacks capacity

Making decisions when patient lacks capacity and lacks surrogate

Capacity

What is “capacity”
Able to understand significant benefits, risks and alternatives to proposed health care

Able to make a decision

Able to communicate a decision

That's the definition

How to implement

When/How to Assess

All patients presumed to have capacity
Clinicians must **rebut** the presumption

No need to **prove** capacity

Must prove **in**capacity

Sometimes obvious

Often unclear

Assess capacity **carefully**
**Not** all or nothing

Patient might have capacity to make **some** decisions but not **others**

Patient may lack capacity for **complex** decisions

**Still** have capacity for **simpler** decisions

Examples

Choose dinner

**Still** have capacity to **appoint** surrogate

Sumner Redstone

May **fluctuate** over time
Patient may have capacity to make decisions in **morning** but not afternoon.

Even if really lacks capacity, **restore** capacity if possible.

Patient has capacity to make decision at hand. **Patients often lack** capacity.

Patient decides **herself**.
Not yet acquired (minors)

Never had (mental disability)

Had but lost (dementia...)

Most common

Adults once had but later lost capacity

Can no longer make own decisions

Mechanisms

3 preferred

Advance directive POLST Agent / DPAHC
2 other

Default surrogate Guardianship

Promises Pitfalls

Advance directive

2 parts to AD

Instruct Appoint

Instruct

FKA “living will”

Record treatment
You want
You do not want
Advantage

Hear from patient **herself**

Best DM for you is **you**

**Obstacle 1**

Not completed

**Obstacle 2**

99497 99498
76% of physicians whose patients **have** ADs do not know they **exist**.

**Not found**

**Complete ≠ Have**

**Obstacle 3**

**Even if completed & available**

**Not clear**

if ___, then ___

If
“Reasonable expectation of recovery”

75% 51% 25% 10%

Then

“No ventilator”

Ever Even if temporary

Vague Ambiguous

Limits

Enough

THE FAILURE OF THE LIVING WILL
By Angela Peskin and Carl E. Schneider

In pursuit of the dreams that patients envision, care can extend beyond their specific expectations. Long-olds have passed from continuity to its traditional version, its safety...
2 parts to AD

“Agent” “DPAHC”

1st choice – patient picks herself

BUT

Usually in an advance directive

Not completed

Still need a SDM

Not found

80%
Overcome some AD limitations by supplementing AD

POLST

What is POLST

Primarily for those expected to die in next year

1 page form front & back

Immediately actionable

No need to “translate” into orders

Provider Orders Life Sustaining Treatment
Recap

Patient cannot speak for herself

No AD

No agent

No POLST

Default surrogate

2nd choice – after agent

Not chosen by patient
Almost all states specify a sequence:

Agent
Spouse
Adult child
Adult sibling
Parent . . . .

More relatives

Close friend

No authoritative list in California
CA not alone

Even **with**
a list

Some have **nobody**

**Still** need a SDM

**Guardian Conservator**

**3rd choice** –
After agent & surrogate

Ask **court** to appoint SDM

**Last resort**

**Prob. Code 4650**
We looked at 5 SDM mechanisms

- Advance directive
- POLST
- Agent / DPAHC
- Default surrogate
- Guardianship

Often **none** of these is available

**Unrepresented**

Increasingly **common** situation
California hospitals & LTC challenged

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

July 2010
Jessica E. Ryan (M.P.H.

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

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

Who are unbefriended patients?

Definition

Prevalence

Causes

Definition

3 conditions

1

Lack capacity
2

No available, applicable AD or POLST

3

No reasonably available authorized surrogate

Nobody to consent to treatment

Big problem

Hospital estimates

16% ICU admits

5% ICU deaths
> 25,000 US, each year

> 3000 CA, each year

End of Life Care Audit – Dying in Hospital

LTC estimates

3 - 4 %
U.S. nursing home population

> 56,000 USA
Growing problem

4 key factors

1

2

3

Outlived
Lost touch
Others “have” family members

Able but unwilling

No contact (e.g. LGBT, homeless, criminal)

Willing but unable

SDM also lacks capacity

We have many unbefriended
Why is that bad?

Risks & Harms

Cannot advocate for self

Have no substitute advocate

"highly vulnerable"
"most vulnerable"

"unimaginably helpless"

Problem

Nobody to authorize treatment

How do clinicians respond?
4 common responses

1 Under-treatment

Reluctant to act without consent

Wait

Until emergency (implied consent)

BUT

Longer period suffering

Increases risks
Ethically “troublesome . . . waiting until . . . condition worsens into an emergency”

Over-treatment

Fear liability
Fear regulatory sanctions

Treat aggressively

BUT

Burdensome
Unwanted

“compromises . . . consideration of patient preferences or best interests”
No discharge to appropriate setting

Takeaway

Need a consent mechanism
Who decides?

LTC

Hospital

LTC

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
Unconstitutional

No written notice to resident

No IDT for anti-psychotics or EOL decisions

Appellate briefing closes today, Jan. 17

That’s LTC
Litigation concerns only 1418.8

But . . . impacts hospitals too

Must capacity determinations be reviewed by courts?

**CONSIDERATIONS FOR REVISING THE HOSPITAL’S POLICY AND PROCEDURE REGARDING DECISION MAKING FOR UNREPRESENTED PATIENTS**

Hospitals that have adopted the (AB)½91 Alliance model policy, “Health Care Decisions for Unrepresented Patients,” may wish to revise their policy. A procedure to address the difficulties in cases was included in the recent Supreme Court case, California Advocates for Serving Home Infants v. Clippers. Hospitals may wish to consider the suggestions outlined below.

**AB 891 (1999)**

“surrogate committee”
BUT patterned on IDT

Oversight & vetting

Solo physician

Variability

Treatment by Committee Will Ignore Constitutional Rights of Elders
By David A. Lash and Eric M. Carlson
Most common approach

"attending physician . . . make decisions for the unbefriended adult patient"

"causes angst for the greater ethics community"

"Having a single health professional make unilateral decisions . . ."

"ethically unsatisfactory in terms of protecting patient autonomy and establishing transparency."
Bias & COI unchecked

Less carefully considered

Second physician consent

Solo physician

Oversight & vetting

Better

Ethics consultant

Multidisciplinary committee
Oversight & vetting

HEALTH CARE DECISIONS FOR UNREPRESENTED PATIENTS

MODEL POLICY FOR GENERAL ACUTE CARE HOSPITALS

Attending physician
Nurse familiar with patient
Social worker familiar with patient
Chair or vice-chair of HEC
Non-medical (community) member of HEC

Tiered model
Combines different mechanisms

Routine treatment → Solo

EOL → MDC

Most/all MDC are "insiders"

External consent
“clinical social worker . . . selected by . . . bioethics committee . . . not be employed”
Conclusion

Some mechanisms are too slow

Other mechanisms are too fast

Fair

Too fair → too slow

Efficiency  Fairness

Expert
Neutral
Careful

Accessible
Quick
Convenient
LASC cannot review every capacity assessment

Trade some fairness for more efficiency

Unlike Goldilocks, we will not agree what is “just right”

Thaddeus Mason Pope, JD, PhD
Director, Health Law Institute
Mitchell Hamline School of Law
875 Summit Avenue
Saint Paul, Minnesota 55105
T 651-695-7661
C 310-270-3618
E Thaddeus.Pope@mitchellhamline.edu
W www.thaddeuspope.com
B medicalfutility.blogspot.com