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

UCLA
Jan. 17, 2018

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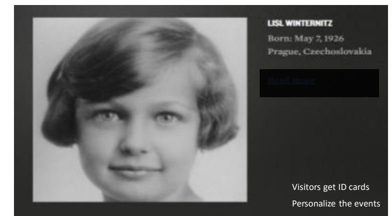
Mitchell Hamline School of Law

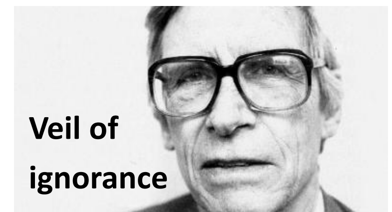
I have no conflicts

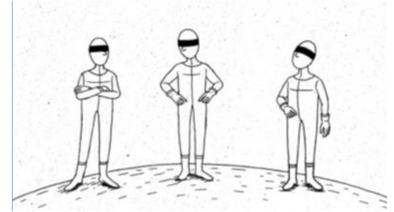


Four sections

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





Try talk to **you** - to ascertain what **you** want

If cannot

Try to **identify** you

Try contact your **family**, so they can guide treatment

If cannot

Use **fair process** to determine treatment

How well does
CA law & policy
measure up?

Roadmap

UCLA LAW
UCLA SCHOOL OF LAW

3

Decision making capacity

Making decisions when patient **lacks** capacity

Making decisions when patient **lacks** capacity and **lacks** surrogate

Capacity

What is "capacity"

Cal. Prob. Code 4609

3

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

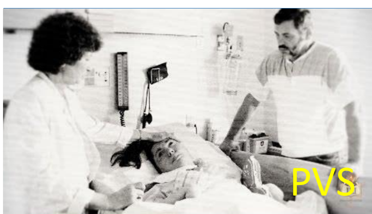
Cal. Prob. Code 4657

Clinicians must **rebut** the presumption

No need to **prove** capacity

Must prove **in**capacity

Sometimes obvious



Often unclear

Assess capacity **carefully**

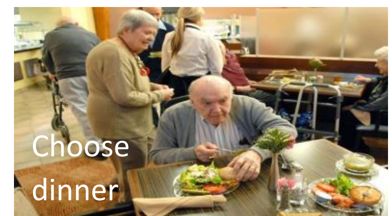
Not all or nothing

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



Still have capacity to **appoint** surrogate

May **fluctuate** over time

Patient may have capacity to make decisions in **morning** but not afternoon

AGS Geriatrics Healthcare Professionals

Leading Change. Improving Care for Older Adults.

POSITION STATEMENT

Making Treatment Decisions for Incapacitated Older Adults Without Advance Directives

AGS Ethics Committee

POSITION 1

Except in cases of obvious and complete incapacity, an attempt should always be made to ascertain the patient's ability to participate in the decision-making process.

Even if really lacks capacity

Restore capacity if possible

Table 7 Means to enhance capacity

Cause of confusion	Possible intervention
Alcohol or other substances intoxification	Detoxification; supplement diet or other intake needs
Altered blood pressure	Treat underlying cause of blood pressure anomaly with medication or other treatment
Altered low blood sugar	Management of blood sugar through diet or medication
Anxiety	Treatment with medications and/or psychotherapy; support groups
Bereavement; Recent death of a spouse or loved one	Support; counseling by therapist or clergy; support group; medications to assist in short term problems (e.g., sleep, depression)
Bipolar disorder	Treatment with medications and/or psychotherapy; support groups
Brain tumor	Surgery and medication
Delirium	Obtain standard labs; obtain brain scan if indicated; assess vitals; treat underlying cause; monitor and reassess over time
Dementia	Treatment with medications for dementia; simplify environment; provide multiple clues within environment; use step-by-step communication
Depression	Treatment with medications and/or psychotherapy; add pleasurable activities to day; ECT if indicated; support groups
Developmental disability	Education and training
Difficulty hearing	Use hearing amplifiers; have hearing evaluated; provide hearing aids; write information down; repeat information; slow down speech; speak clearly and distinctly
Difficulty seeing	Use magnifying glass; have sight evaluated; provide glasses; provide spoken information; repeat information; ensure sufficient lighting; use large print; have access to Braille materials
Difficulty understanding English	Use translator
Head injury	Treatments for acute effects (e.g., blood, pressure, swelling) as necessary; monitoring over time; rehabilitative speech, physical, occupational therapies

HEC Forum
DOI 10.1007/s10730-016-9317-9

Patient has capacity to make decision at hand

↓

Patient decides **herself**

Patients often **lack** capacity

3

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

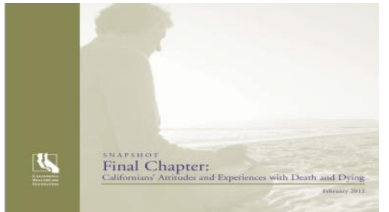
Advantage

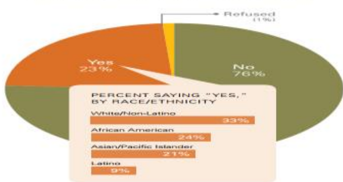
Hear from patient **herself**

Best DM for you is **you**

Obstacle 1

Not completed

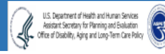




Obstacle 2

Not found

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



Fail to make & distribute copies

- Primary agent
- Alternate agents
- Family members
- PCP
- Attorney
- Clergy
- Online registry

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 Fagerlin and Carl E. Schneider

In pursuit of the dream that patients' exercise of autonomy could extend beyond their span of competence, living wills have passed from controversy to conventional wisdom, to widely promoted policy. But the policy has not produced results, and should be abandoned.

HASTINGS CENTER REPORT March-April 2004

Annals of Internal Medicine | Perspective

Controlling Death: The False Promise of Advance Directives

Henry S. Perkins, MD

Advance directives promise patients a say in their future care but actually have had little effect. Many experts blame problems with completion and implementation, but the advance directive concept itself may be fundamentally flawed. Advance directives simply presuppose more control over future care than is realistic. Medical crises cannot be predicted in detail, making most prior instructions difficult to adapt, irrelevant, or even misleading. Furthermore, many proxies either do not know patients' wishes or do not pursue those wishes effectively. Thus, unexpected problems arise often to defeat advance directives, as the case in this paper illustrates. Because advance directives offer only limited benefit, advance care planning should emphasize not the completion of directives but the emotional preparation of patients and families for future crises. The existentialist Albert Camus might suggest that physicians should warn patients and families that momentous, unforeseeable decisions lie ahead. Then, when the crisis hits, physicians should provide guidance; should help make decisions despite the inevitable uncertainties; should share responsibility for those decisions; and, above all, should courageously see patients and families through the fearsome experience of dying.

Ann Intern Med. 2007;147:51-57.

For author affiliation, see end of text.

2 parts
to AD

~~Instruct~~
Appoint

"Agent"
"DPAHC"

1st choice –
patient picks
herself

BUT

Usually in an
advance
directive

Not completed
Not found

Still need
a SDM

80%

Overcome some AD limitations by **supplementing** AD

POLST

Provider
Orders
Life
Sustaining
Treatment

What is POLST

1 page form front & back

Primarily for those expected to die in next year

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

Chosen off

a list

Almost all states specify a **sequence**

Agent
Spouse
Adult child
Adult sibling
Parent . . . . .

More relatives

Close friend

No authoritative list in California

Closest Available Relati

Health Care Decisions

No statutory hierarchy[1]

- Spouse/domestic partner
- Adult child
- Either parent
- Adult sibling
- Grandparent
- Adult aunt/uncle
- Adult niece/nephew

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

Slow
Expensive
Cumbersome

Recap

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

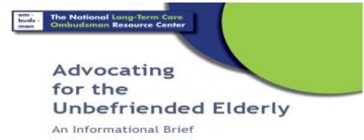
“unbefriended”

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

August 2010

Jessica E. Brill Ortiz, MPA

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

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

Decisions to limit life-sustaining treatment for critically ill patients who lack both decision-making capacity and surrogate decision-makers*

Douglas B. White, MD; J. Randall Curtis, MD, MPH; Bernard Lo, MD; John M. Luce, MD

5% ICU deaths

ARTICLE | Annals of Internal Medicine

Life Support for Patients without a Surrogate Decision Maker: Who Decides?

> 25,000

US, each year

> 3000

CA, each year

End of Life Care Audit – Dying in Hospital

National report for England 2016

3.4. Is there documented evidence that the cardiopulmonary resuscitation (CPR) decision by a senior discussed with the **nominated person(s) important to the patient** during the last episode of care?

• YES	78%*	7219
• NO	18%	1706
• NO BUT	4%	377

If 'no but' during the last episode of care it was recorded that:

• There was no nominated person important to the patient	47%	177
• Attempts were made to contact the nominated person important to the patient but were unsuccessful	53%	200

LTC

estimates

Incapacitated and Alone:

Health Care Decision-Making for the Unbefriended Elderly

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American Bar Association
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July 2003

3 - 4 %

U.S. nursing home population

SAFER • HEALTHIER • PEOPLE™

CDC Monitoring the Nation's Health

Long-Term Care Providers and Services Users in the United States: Data From the National Study of Long-Term Care Providers, 2013–2014

Vital and Health Statistics

Series 3, Number 38

February 2016

1.4 million

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Centers for Disease Control and Prevention
National Center for Health Statistics

> 56,000

USA

> 6700

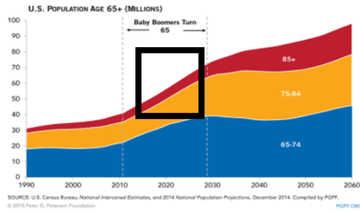
CA

Not just big, but

Growing problem

4 key factors

1



2

INSIGHT

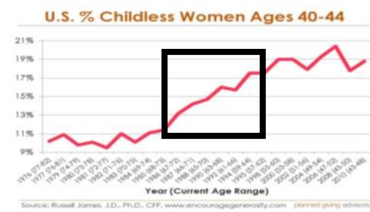
AARP Public Policy Institute

10,000,000
Boomers live **alone**

The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers

Donald Redfoot, Lynn Feinberg, and Ari Houser
AARP Public Policy Institute

3



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

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"highly vulnerable"

"most vulnerable"

GUARDIANSHIP FOR VULNERABLE ADULTS IN NORTH DAKOTA: RECOMMENDATIONS REGARDING UNMET NEEDS, STATUTORY EFFICACY, AND COST EFFECTIVENESS

WINSOR C. SCHMIDT

"unimaginably helpless"

Problem

Nobody to authorize treatment

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**"

2

Over-treatment

Fear liability

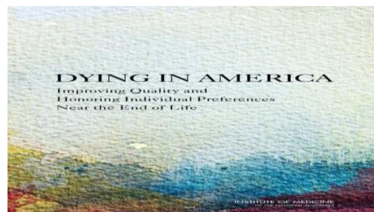
Fear regulatory sanctions

Treat aggressively

BUT

Burdensome

Unwanted



"**compromises** . . . consideration of patient preferences or best interests"

3

No discharge
to appropriate
setting

4

Takeaway

No consent ➡ Bad conduct

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

IN THE COURT OF APPEAL OF THE STATE OF CALIFORNIA
FIRST APPELLATE DISTRICT
DIVISION FOUR

CALIFORNIA ADVOCATES FOR NURSING HOME REFORM, et al.
Plaintiffs and Appellants,
vs.
KAREN SMITH, MD., MPH, as Director of the California Department of Public Health,
Defendants and Appellants.

Case No. A147987

Alameda County Superior Court, Case No. RG13700100

ON APPEAL FROM THE JUDGMENT OF THE SUPERIOR COURT
COUNTY OF ALAMEDA
Hon. Evelio M. Grillo, Presiding

Unconstitutional

No written notice to resident

No IDT for anti-psychotics or EOL decisions

Appellate briefing closes **today**, Jan. 17

Legislative activity **too**

Sen. Hernandez
S.B. 503

Senator Pan
S.B. 481

That’s LTC

Litigation concerns **only 1418.8**

But . . . impacts **hospitals** too

Must capacity determinations be reviewed by **courts**?

APPENDIX 2-E

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

Hospitals that have adopted the CMA/CHA/Alliance model policy, "Health Care Decisions for Unrepresented Patients," may wish to revise their policy & procedure to address the deficiencies in state law identified in the recent Superior Court case, *California Advocates for Nursing Home Reform v. Chapman*. Hospitals may wish to consider the suggestions outlined below.

Hospital

AB 891 (1999)

CHAPTER 4. HEALTH CARE DECISIONS FOR PATIENTS WITHOUT SURROGATES

§ 4720. Application of chapter ....
§ 4721. Referral to surrogate committee ....
§ 4722. Composition of surrogate committee ....
§ 4723. Standards of review by surrogate committee ....
§ 4724. Decisionmaking by surrogate committee ....
§ 4725. General surrogate rules applicable to surrogate committee ....

6

"surrogate committee"

BUT

patterned

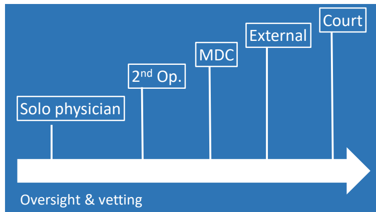
on IDT

Treatment by Committee Will Ignore Constitutional Rights of Elders

By David A. Lash and Eric M. Carlson

Variability

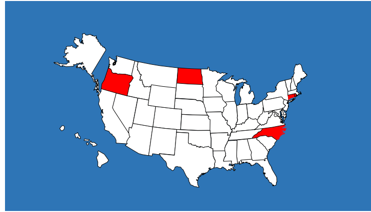
Oversight & vetting

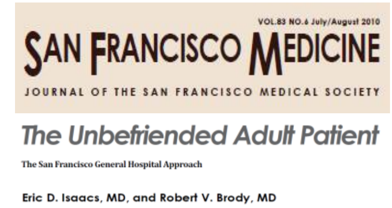


Solo

physician

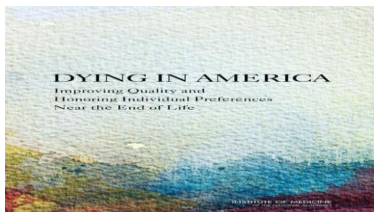
Most
common
approach





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

"causes **angst** for the greater ethics community"



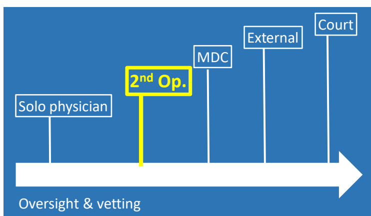
"Having a **single health professional** make unilateral decisions . . ."

"**ethically unsatisfactory** in terms of protecting patient autonomy and establishing transparency."

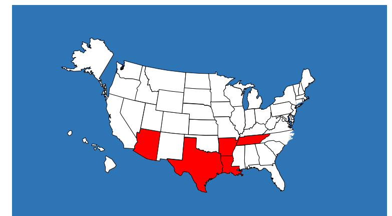
Bias & COI unchecked

Less carefully considered

Second physician consent



Better



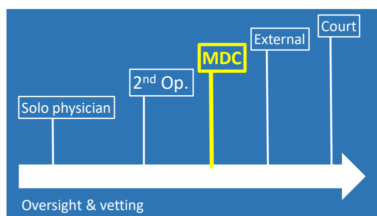
Ethics consultant

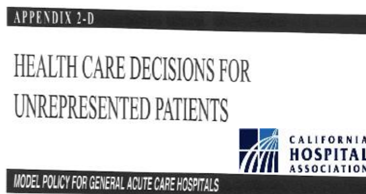
Guidelines for Physicians: Forgoing Life-Sustaining Treatment for Adult Patients

Joint Committee on Biomedical Ethics
of the
Los Angeles County Medical Association
and
Los Angeles County Bar Association

Approved by the Los Angeles County Medical Association February 15, 2006
Approved by the Los Angeles County Bar Association March 22, 2006

Multidisciplinary committee





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

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

Policy 1319

Tiered model

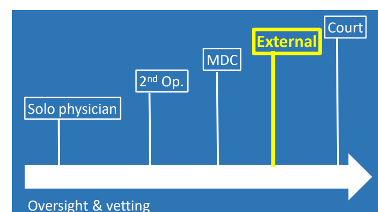
Combines different mechanisms

Routine treatment ➡ Solo

EOL ➡ MDC

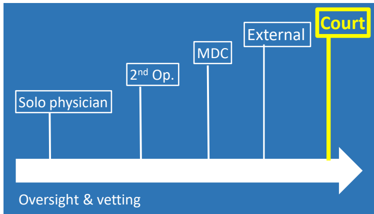
Most/all MDC are "**insiders**"

External consent

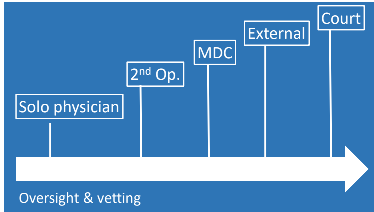


"**clinical social worker** . . . selected by . . . bioethics committee . . . **not** be employed"

Court



Recap

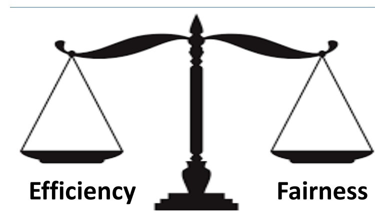


Who's right?

Conclusion

Some mechanisms are **too slow**

Other mechanisms are **too fast**



Fair

Expert
Neutral
Careful

Too fair → too slow

Accessible
Quick
Convenient

LASC cannot review every capacity assessment

Trade **some** fairness for more efficiency

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