Health law  
Bioethics  
Not guardianship

Increasingly common situation

Minnesota hospitals & LTC challenged

Patient needs treatment

Better Healthcare Decision Making for Incapacitated Patients without Surrogates

3rd Annual WINGS Minnesota Guardianship Summit
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Healthcare facility has incapacitated patient with no available surrogate
BUT

No capacity
No surrogate
Patient cannot consent

Nobody else to consent

Various terms

“unrepresented”
“adult orphan”

Patient w/o proxy
Incapacitated & alone

“I use
“unbefriended”
My Perspective

I am a **law** professor.

But I often speak and write directly to **clinicians**
Who?

Roadmap

5 parts

1 Substitute decision making

2 Who are the unbefriended

Who can consent for the incapacitated patient with no surrogate?

Perspective today – from the clinician
Unit 1 of 5

Substitute Decision Making

How to make healthcare decisions for patients without capacity

Capacity

Ability to understand the significant benefits, risks and alternatives to proposed health care

Risks to patient safety

Prevention measures

Decision making mechanisms
Ability to **make and communicate** a decision

If decision not impaired by cognitive or volitional defect, providers **must respect** decision

Not honoring choice = **paternalism**, violation of patient autonomy

All patients are **presumed** to have capacity

Until the presumption is rebutted

Patient has capacity to make the decision at hand

Patient decides **herself**

**BUT patients often lack** capacity

1. Had but **lost** (dementia...)
2. Not **yet** acquired (minors)
3. **Never** had capacity (mental disability)

Let’s focus on the most common one

Adults who had but **lost** capacity
Mechanisms when patient cannot make her own decisions

Advocate / DPAHC

Default surrogate

Advance directive

Maybe left prior instructions

Advantage

Patient herself decided (earlier)

BUT

Not completed

Not found

Not clear

Obstacle 1
Not completed

AARP

30%

28%

Obstacle 2

18-29  15%
30-49  33%
50-64  38%
65-74  61%
75+    58%

Not found

65-76% of physicians whose patients have advance directives do not know they exist

Individuals fail to make & distribute copies

Primary agent
Alternate agents
Family members
PCP

Attorney
Clergy
Online registry

U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy
Obstacle 3
Not clear

If

if ___,
then ___

Then

Preferences vague
“No ventilator”
   Ever
   Even if temporary

Limits

Trigger terms vague
“Reasonable expectation of recovery”
   75%  51%
   25%  10%

Plus: prognosis uncertain
Instruct
Appoint

2 parts to AD

Need a SDM

1st choice – patient picks herself

Patient knows who
(1) They trust
(2) Knows their preferences
(3) Cares about her

“Agent”

“DPAHC”

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

Enough
THE FAILURE OF THE LIVING WILL

By Angela Feigelin and Carl E. Schneider

INSTRUCTIONS

2/2/2017

Parts to AD

Instruct
Appoint

Need a SDM

1st choice – patient picks herself

Patient knows who
(1) They trust
(2) Knows their preferences
(3) Cares about her

“Agent”

“DPAHC”
BUT

Usually in an advance directive

Not completed
Not found
Not clear

Still need a SDM

Default surrogate

2nd choice – if no agent, turn to default priority list

“Surrogate”

“Proxy”

Most states specify a sequence

Agent
Spouse
Adult child
Adult sibling
Parent . . . . .
No authoritative list in Minnesota

**BUT**

Custom & practice

Judicially endorsed

**Still** need a SDM

Guardian

3\textsuperscript{rd} choice – ask *court* to appoint SDM
Last resort

Not sufficiently responsive

3 types SDM

<table>
<thead>
<tr>
<th>Who appoints</th>
<th>Type of surrogate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient</td>
<td>Agent DPAHC</td>
</tr>
<tr>
<td>Legislature</td>
<td>Surrogate Proxy</td>
</tr>
<tr>
<td>Court</td>
<td>Guardian Conservator</td>
</tr>
</tbody>
</table>

How does the SDM decide?

Any type of SDM can usually make any decision patient could have made

Hierarchy
1. Subjective
2. Substituted judgment
3. Best interests

SDM steps into shoes of patient
Subjective
If patient left instructions, follow them

Substituted Judgment
Do what patient would do (using known values, preferences)

Best interests
If cannot exercise substituted judgment, then objective standard

Unit 2 of 5

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

Step by step flowchart

1

Does the patient have capacity?
If yes, then **patient** makes treatment decision.

If no, can patient decide with “support”?

If yes, then **patient** makes treatment decision.

If no, proceed 2

Is there an available AD or POLST

Does the AD or POLST clearly **apply** here

If yes, follow AD or POLST (but involve surrogate)

If no, proceed
If patient lacks capacity, a **SDM** must make the treatment decision.

**Is there a court-appointed guardian?**

If so, is the guardian reasonably available?

If no guardian . . .

**Is there a healthcare agent (DPOAHC)?**

If so, is the agent reasonably available?

If no agent . . .

**Is there anyone on the default surrogate priority list?**
If so, is the surrogate reasonably available? Have social workers diligently searched for surrogates

If yes, then →

Nobody to consent to treatment

Is the situation an emergency

If yes →

Is there any reason to believe the patient would object

If no, proceed on basis of implied consent
Is there a responsive guardianship system? If so, seek a court appointed guardian.

Even if a guardian is forthcoming, may need to make decisions in the interim.

Big problem

Hospital estimates

16% ICU admits

5% ICU deaths

> 25,000
3 - 4%  
U.S. nursing home population

> 56,000  
in USA

Extrapolate  
5.5 / 320  
1.7%
Growing problem

Just 4 causal factors

1

10,000,000 Boomers live alone

Outlived Lost touch
No **contact** (e.g. LGBT, homeless, criminal)

Also lack **capacity**

**Unwilling**

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**Unit 3 of 5**

**Risks & Harms**
Cannot advocate for self

Have no substitute advocate

“highly vulnerable”
“most vulnerable”

Problem

Nobody to authorize treatment

3 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 the patient’s medical condition worsens into an emergency so that consent to treat is implied . . .”

2

Over-treatment
Fear of liability
Fear of regulatory sanctions

Treat aggressively

BUT

Burdensome
Unwanted

“compromises patient care and prevents any thorough and thoughtful consideration of patient preferences or best interests”

3
No discharge to appropriate setting
Avoid **being** unbefriended

Avoid **risks** of unbefriended

1. **Assess capacity more carefully**

Better capacity assessment
Diligent search for surrogates
More advance care planning
Better default surrogate lists

Distinguish 2 related terms
**Competence**
- *Legal* determination (by a court)
- Global (all decisions)

**Capacity**
- *Clinical* determination
- Decision specific *(not)* global

**Capacity**
- relevant in healthcare

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**Not all or nothing**
- Patient might have capacity to make *some* decisions but not others
- Patient may lack capacity for complex decisions
- But have capacity to appoint a surrogate

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**Decision specific**
- May *fluctuate* over time

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*Margot Bentley*
- stage 7 Alzheimer's
capacity to consent to hand feeding
Patient might have capacity to make decisions in **morning** but not afternoon

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**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.

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**More Advance care planning**

**Before** lose capacity:

Record preferences and/or
Name agent

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**Diligent search for surrogates**

Surrogates usually found for most **thought** to be unbefriended
Even if no surrogate found, search may reveal evidence of patient’s values, preferences

The standard of decision-making regarding treatment should consider any present indications of benefits and burdens that the patient can convey and should be based on any knowledge of the patient’s prior articulations, cultural beliefs if they are known, or an assessment of how a reasonable person within the patient’s community would weigh the available options.

4 Better default surrogate laws

Clinical solutions
Better capacity assessment
Diligent search for surrogates
More advance care planning

Legal solutions

Law as causal factor

Variability

Some states will have fewer unrepresented patients
Some states will have zero unrepresented patients

Why?

Default surrogate laws

Longer

More flexible

Bigger net → catch more fish

Longer list

More relatives

Spouse
Adult child
Parent
Adult sibling
Grandparent / adult grandchild
Aunt / uncle, niece / nephew
Adult cousin

ND list is longer than most

9 categories deep
Tennessee

“surrogate shall be identified by the supervising health care provider”

“criteria ... in the determination of the person best qualified to serve as the surrogate”

POSITION 2

It should not be assumed that the absence of traditional surrogates (i.e., 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.

More flexible

Close friend
Ability to make decisions
Regular contact with patient
Demonstrated care and concern
Availability to visit the patient
Availability to engage in face-to-face contact with providers

Limited

Colorado 2016

No default surrogate statute

Custom & practice
2. Without an advance directive that designates a proxy, the patient's family should become the surrogate decision maker. Family includes persons with whom the patient is closely associated. In the case when there is no one closely associated with the patient, but there are persons who both care about the patient and have some relevant knowledge of the patient, such relations should be involved in the decision-making process, and may be appropriate surrogates.

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**Decision making mechanisms**

Tried to **prevent** from being unbefriended

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**BUT**
How to make healthcare decisions

Solo physician
Second physician
Ethics committee
External consent

Solo physician
Most common approach

Odd

Oversight vs. Vulnerability

Scrutiny
Vetting
"Having a single health professional make unilateral decisions . . . is ethically unsatisfactory in terms of protecting patient autonomy and establishing transparency."

Bias
COI
Careless

Prohibited in ND and some states

ID-05-044. Restrictions on who can act as agent.
A person may not exercise the authority of agent while serving in one of the following capacities:
1. The principal's health care provider;
2. A relative of the principal who is an employee of the principal's health care provider;
3. The principal's long-term care services provider; or
4. A relative of the principal who is an employee of the principal's long-term care services provider.

20-1-32-11 (5-31) (Who may be guardian - Priorities.
1. Any competent person or a designated person from a suitable institution, agency, or
nonprofit group home may be appointed guardian of an incapacitated person. No
institution, agency, or nonprofit group home providing care and custody of the
incapacitated person may be appointed guardian. However, if no one else can be

Second physician consent

3
“clinical social worker . . . selected by the provider’s bioethics committee and must not be employed by the provider”

S.B. 503
“independent” medical consultant + “independent” patient advocate
CANHR not sat b/c “paid” by NH

4 Multidisciplinary committee
Physician not attending with consensus ethics committee

CONSTITUTIONAL DUE PROCESS

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

Conclusion

EFFICIENCY

FAIRNESS

BUT

California IDT
Fair

Expertise, neutrality, careful deliberation

Too fair → too slow

Accessible, quick, convenient, cost-effective

Sacrifice some fairness for efficiency

References


