Better Decision Making for Incapacitated Patients without Surrogates
Minnesota Elder Justice Center
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Who is the speaker?

Director, Health Law Institute
Mitchell Hamline School of Law

2012 - present

Before that:

Pittsburgh, PA

Georgetown bioethics

Georgetown Law

7th Circuit
I am a law professor. But I often speak and write directly to clinicians.

Perspective today – from the clinician

November 22, 2016
Roadmap

1. Informed consent
2. Capacity
3. Substitute decision making

Identifying the problem

Fairview Lakes Medical Center
Fairview Northland Medical Center
Fairview Ridges Hospital
Fairview Southdale Hospital
Maple Grove Hospital
Univ. Minnesota Masonic Children's Hospital
University of Minnesota Medical Center
Fairview Range Medical Center

7

Foundational background

4. Who are “unbefriended”
5. Prevalence and causes
Risks & solutions

6. Risks & ethical challenges
7. Solutions

Unit 1 of 7

Informed Consent

History

1847

Do NOT consider patient’s “own crude opinions”
1905 Battery No consent at all

4 variations

(1) No consent to any procedure

(2) Consent only to different procedure

“Every human being of adult years and sound mind has a right to determine what shall be done with his own body . . . .”

Richard Dreyfus
RTD cases 1970s

Patient consented to biopsy not removal

Mary Schloendorff
Consent = vaginal, but do CS

Seaton v. Patterson
(Ky. App. 2012)

Consent circumcision but did penectomy

(3) Same procedure, different body part

Mohr v. Williams (Minn. 1905)

Patient consented to left ear
Physician operated on right ear

(4) Same procedure, same part, different doc

As of 100 years ago, law required physicians to get consent

It did not yet require that the consent had to be informed
Distinguish 2 related terms

Competence
- Legal determination (by a court)
- Global (all decisions)

Capacity
- Clinical determination
- Decision specific (not global)

What is capacity
- Ability to understand the significant benefits, risks and alternatives to proposed health care
- Ability to make and communicate a decision.

1972

Unit 2 of 7

Capacity

Exhibit 10: Decision-making capacity. ‘Decision-making capacity’ means the ability to understand the significant benefits, risks, and alternatives to proposed health care and to make and communicate a health care decision.
Decision specific
Fluctuates over time

Patient might have capacity to make some decisions but not others

Patient might have capacity to make decisions in morning but not afternoon

Capacity is a clinical decision
With legal consequences

3 case examples

Lane v. Candura
(Mass. 1978)

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

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

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

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

Significance of capacity

If patient’s decision is not impaired by cognitive or volitional defect, providers must respect decision

Otherwise, not honoring choice = paternalism, violation of patient autonomy

All patients are presumed to have capacity
Until the presumption is rebutted

Example: presumption of capacity

Margot Bentley, stage 7 Alzheimer’s
capacity to consent to hand feeding

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

Unit 3 of 7

If patient cannot make her own decisions, she needs a SDM

3 main types SDM

1st choice – patient picks herself

Usually in an advance directive

“Agent”

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

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 MN list

ND list is longer than most
9 categories deep

23-10-13. Persons authorized to provide informed consent to health care for incapacitated persons: Priority.
1. Informed consent for health care for a minor patient or a patient who is determined by a physician to be an incapacitated person, as defined in subsection 2 of section 30-1-20, and unable to consent may be obtained from a person authorized to consent on behalf of the patient. Persons in the following classes and in the following order of priority may provide informed consent to health care on behalf of the patient:
   a. The individual, if any, to whom the patient has given a durable power of attorney that encompasses the authority to make health care decisions, unless a court of competent jurisdiction specifically authorizes a guardian to make medical decisions for the incapacitated person;
   b. The appointed guardian or custodian of the patient, if any;
   c. The patient’s spouse who has maintained significant contacts with the incapacitated person;
   d. The patient’s parent who has maintained significant contacts with the incapacitated person;
   e. Children of the patient who are a least eighteen years of age and who have maintained significant contacts with the incapacitated person;
   f. Parents of the patient, including a step-parent who has maintained significant contacts with the incapacitated person;
   g. Adult brothers and sisters of the patient who have maintained significant contacts with the incapacitated person;
   h. Grandchildren of the patient who are at least eighteen years of age and who have maintained significant contacts with the incapacitated person; and
   i. A close relative or friend of the patient who is at least eighteen years of age and who has maintained significant contacts with the incapacitated person.
3rd choice – ask **court** to appoint SDM (rare)

“Guardian”
“Conservator”

SDM summary

### How does the SDM decide?

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

### Who appoints

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

### Hierarchy

1. Subjective
2. Substituted judgment
3. Best interests

**Subjective**

If patient left **instructions** addressing situation, follow those instructions
**Substituted Judgment**
Do what patient *would have* decide (if she could) using known values, preferences

**Best interests**
If cannot exercise substituted judgment, then objective standard

**Unit 4 of 7**

**Who are unrepresented incapacitated patients?**

**Unbefriended**
Unrepresented
Adult orphan

**Patient w/o proxy**
Incapacitated & alone

**Terminology**

**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

4

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 an functioning guardianship system?

Usually Not

If so, seek a court appointed guardian.

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

How often are you seeing this?

Unit 5 of 7
Prevalence & causes

Big problem

16% ICU admits

5% ICU deaths

> 25,000

3 - 4% U.S. nursing home population

> 56,000 in USA

1.4 million
10,000,000 Boomers live **alone**

Outlived
Lost touch

**3**

**4**

Others **“have” family members**

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

Surrogates also lack **capacity**

**Unwilling**
Law as causal factor

Variability from state to state

Some states will have fewer unrepresented patients

Some states will have zero unrepresented patients

Why?

Longer default surrogate lists

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

Close friend

Social worker
Ethics committee

Existence of public guardian system

Slow
Expensive

Unit 6 of 7

Ethical Problems

Nobody to authorize treatment

3 ways to respond
1. No treatment

Wait until emergency (implied consent)

Longer period suffering
Increases risks

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

Under-treatment

Ethically “troublesome... waiting until the patient’s medical condition worsens into an emergency so that consent to treat is implied...”
Over-treatment

Physician acts without consent

Most common approach

Fear of liability

Fear of regulatory sanctions

Bias

COI

Careless

"unimaginably helpless"

"highly vulnerable"

"most vulnerable"
“Having a single health professional make unilateral decisions . . . is ethically unsatisfactory in terms of protecting patient autonomy and establishing transparency.”

Prohibited in ND and some states

23-36.44. 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 nonrelative of the principal who is an employee of the principal’s health care provider;
3. The principal’s long-term care services provider;
4. A nonrelative of the principal who is an employee of the principal’s long-term care services provider.

30.1-CB-11, (S-311) 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 appointed, the court may appoint an institution, agency, or nonprofit group home as guardian.

Better than under- or over-treatment

Scrutiny Vetting

California IDT
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

Got struck as unconstitutional – inadequate due process

On appeal (A147987)
Legislation to add more oversight (S.B. 503)
“independent” medical consultant + “independent” patient advocate
(CANHR still not sat b/c “paid” by NH)

Problem long neglected

In addition to new laws

Colorado 2016
Incapacitated and Alone: Health Care Decision-Making for the Unbefriended Elderly

Naomi Karp and Erica Wood

2017 American Bar Association Commission on Law and Aging
July 2003

Advocating for the Unbefriended Elderly
An Informational Brief

August 2010
Jessica E. Brit Driscoll, MPH

2016 AGS Geriatrics Healthcare Professionals
Leading Change. Improving Care for Older Adults.

Prevention

Advance care planning before lose capacity

2

Diligent search for surrogates
NHs, neighbors, service agencies
Access home, apartment
Personal effects
Health records, pension plans

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

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

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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.

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Assess capacity more carefully
Not all or nothing

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Patient may lack capacity for complex decisions
But **have** capacity to appoint a surrogate

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If you need a SDM

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**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.

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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.
Mechanisms short of guardianship

To expensive
Too slow

Conclusion

Efficiency
Fairness

Accessible, quick, convenient, cost-effective

POSITION 3
After a conscientious effort has failed to identify an appropriate surrogate, a group of individuals who care for the patient may determine appropriate treatment goals and design a humane care plan to meet those goals. This group might consist of a multidisciplinary healthcare team, including physician, nurse, nurse’s aide, clergy, and others who have worked most closely with the patient. If an institutional
Expertise, neutrality, careful deliberation

References


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