Better Decision Making for Incapacitated Patients without Surrogates

North Dakota Long Term Care Association
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Thaddeus Mason Pope, JD, PhD
Mitchell Hamline School of Law

Disclosures

Nothing to disclose

Just travel expenses to develop new ATS-AGS Policy Statement on this

Objectives

Decision making capacity
Surrogate decision making
Mechanisms for medical decision making when neither the patient nor any legally authorized substitute decision maker is available

The challenges of incapacitated patients without surrogates is caused & exacerbated by the law
But this is the NDLTCA “ethics session”
So, while the question of who is an authorized decision maker is largely framed by the law, this is not a legal presentation.

In any case I am not licensed in ND

Who is the speaker?

Director, Health Law Institute
Mitchell Hamline School of Law

2012 - present

Before that:

Georgetown bioethics

Pittsburgh, PA
I am a law professor. But I often speak and write directly to clinicians.
3:00 PM to 5:00 PM

7

Foundational background

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

Identifying the problem

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 . . . .”

Seaton v. Patterson
(Ky. App. 2012)
(3) Same procedure, different body part

(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

1960s
That was just a historical sketch, Now, let’s look at this doctrinally.

1972

Comparing battery & informed consent

Battery

PTF: “I did not consent to what doc did”

Informed consent

PTF: “I did consent . . .”
“BUT I would not have consented, if disclosure had been appropriate [non-negligent]”

Core complaint:
Physician failed to disclose information

Duty

But legally actionable only if physician had a duty to disclose that information

Inherent risks from proposed treatment
- Probability
- Severity

Benefits & risks of each alternative
One alternative is doing nothing

ND reasonable patient standard

Duty measured by patient needs

Duty to disclose what would a reasonable patient consider important / significant in making this treatment decision
Canterbury v. Spence

1% risk paralysis

Reasonable prudent patient would want to know that risk

Therefore, physician has duty to disclose it

Duty measured by what hypothetical reasonable patient would deem material, significant in making this treatment decision

Unit 2 of 7

Capacity
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.

**Decision specific**

- 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 \textit{clinical} decision

With legal consequences

3 case examples

\textbf{Lane v. Candura}
(Mass. 1978)

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

Doc thinks stupid decision
But she \underline{understands} the diagnosis & consequences
So, she \underline{has} capacity

\textbf{DHS v. Northern}
(Tenn. 1978)

Mary Northern 72yo
Gangrene both feet
Amputation required to save life

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

\textbf{In re Maynes-Turner}
(Fla. App. 1999)
**Doc:** “She might pose significant risks for herself on the basis of those decisions that she would make.” So no discharge home.

**Doc:** “Cognitively she does reasonably well. She would seem to possess the necessary knowledge that would be required for restoration.”

### 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 for ND LTC

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 . . . . .

ND list is longer than most
9 categories deep

3rd choice – ask court to appoint SDM (rare)
“Guardian”
“Conservator”

**SDM summary**

<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

**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?

Terminology

Definition

3 conditions

Unbefriended
Unrepresented
Adult orphan

Patient w/o proxy
Incapacitated & alone

Burdens of treatment Benefits

3 conditions
1. Lack capacity

2.

3. No available, applicable AD or POLST

None to consent to treatment

Step by step flowchart
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 \(\rightarrow\)

Nobody to consent to treatment

4

Is the situation an emergency?

If yes \(\rightarrow\)

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

> 500
(extrapolated)

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

1.4 million

Long-Term Care Providers and Services Users in the United States: Data from the National Study of Long-Term Care Providers, 2013-2014.
North Dakota has one of the highest percentages of older people.
10,000,000 Boomers live alone

Outlived
Lost touch

Others “have” family members

No contact (e.g. LGBT, homeless, criminal)
Also lack capacity
Unwilling
5

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

Under-treatment

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

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

Oversight vs. Vulnerability

Oversight vs. Vulnerability
“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

23-36.4A. 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;
4. A relative of the principal who is an employee of the principal’s long-term care services provider.

30.1-26-11 (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 found, the institution, agency, or nonprofit group home may be appointed guardian.

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

Scrutiny Vetting

California IDT
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)

How do you handle this?

Unit 7 of 7

Solutions

Problem long neglected

In addition to new laws

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Position Statement

Making Treatment Decisions for Incapacitated Older Adults Without Advance Directives
AGS Ethics Committee
JAGS 44:986-987, 1996
© 1996 by the American Geriatrics Society

BACKGROUND
General principles are often faced with the problem of making medical decisions for patients who lack doctors, patients’ wishes, or in states, where close family or relatives are involved.
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. Brit Orto, MPH

Advance care planning before lose capacity

Prevention 1

Diligent search for surrogates

2
Even if no surrogate found, search may reveal evidence of patient’s values, preferences

3

Assess capacity more carefully
Not all or nothing

If you need a SDM

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

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.

If you need a SDM

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Mechanisms
short of guardianship

Too expensive
Too slow

POSITION 1
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

Conclusion
Efficiency
Fairness
Accessible, quick, convenient, cost-effective

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Low - attending
Medium - proxy
High – proxy, 2d op, ethics committee

Florida Stat. 765.401 (a) guardian (b) spouse (c) adult child (d) parent (e) adult sibling (f) adult relative (g) close friend (h) clinical social worker . . . selected by the provider’s bioethics committee and must not be employed by the provider
Expertise, neutrality, careful deliberation

References


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
