Better Decision Making for Incapacitated Patients without Surrogates

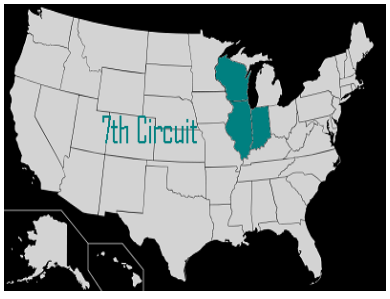
Minnesota Elder Justice Center
December 9, 2016

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

Who is the speaker?

Director, Health Law Institute
Mitchell Hamline School of Law

Before that:



I am a **law** professor.

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

The NEW ENGLAND JOURNAL of MEDICINE

JAMA® The Journal of the American Medical Association

AMERICAN THORACIC SOCIETY 1905 ATS

AMERICAN COLLEGE OF CHEST PHYSICIANS

Perspective today – from the **clinician**

AGS THE AMERICAN GERIATRICS SOCIETY
Geriatrics Health Professionals. Leading change. Improving care for older adults.

November 22, 2016

ORIGINAL ARTICLE

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

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Key words: unbefriended; capacity assessment; surrogate decision maker; substituted judgment; best interest;

In this position statement, we define unbefriended older

FAIRVIEW

- 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

Roadmap

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

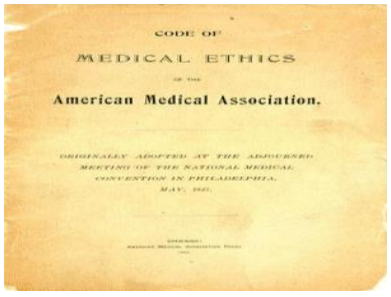
6. Risks & ethical challenges
7. Solutions

Unit 1 of 7

Informed Consent

History

1847


CODE OF
MEDICAL ETHICS
OF THE
American Medical Association.

ORIGINALLY ADOPTED AT THE ADJOURNED MEETING OF THE NATIONAL MEDICAL CONVENTION IN PHILADELPHIA, MAY, 1847.

Do **NOT** consider patient's "own crude opinions"

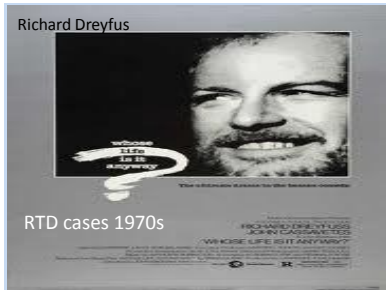
1905

Battery

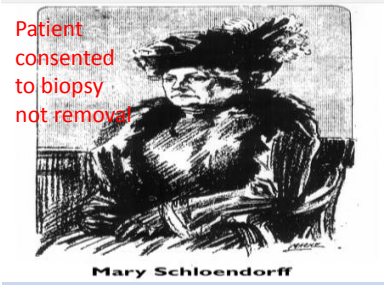
No consent **at all**

4 variations

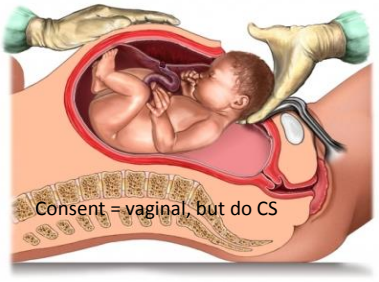
(1) No consent to **any** procedure



(2) Consent only to **different** procedure



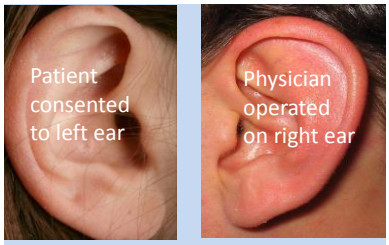
"Every human being of adult years and sound mind has a right to determine what shall be done with his own body . . . . "



Seaton v. Patterson

(Ky. App. 2012)

(3) Same procedure, **different body part**



Mohr v. Williams (Minn. 1905)

(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**

1972

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.

CHAPTER 145C

HEALTH CARE DIRECTIVES

Subd. 1b. **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

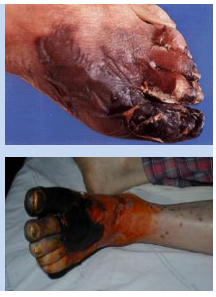
Lane v. Candura

(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

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

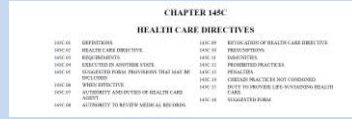
2nd choice – if no agent, turn to **default priority** list

"Surrogate"

"Proxy"

Most states specify a sequence

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


CHAPTER 145C

HEALTH CARE DIRECTIVES

No authoritative MN list

ND list is **longer** than most

9 categories deep

23-12-13. 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 30.1-26-01, 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. Children of the patient who are at least eighteen years of age and who have maintained significant contacts with the incapacitated person;
   e. Parents of the patient, including a stepparent who has maintained significant contacts with the incapacitated person;
   f. Adult brothers and sisters of the patient who have maintained significant contacts with the incapacitated person;
   g. Grandparents 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; or
   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

Who appoints	Type of surrogate
Patient	Agent DPAHC
Legislature	Surrogate Proxy
Court	Guardian Conservator

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

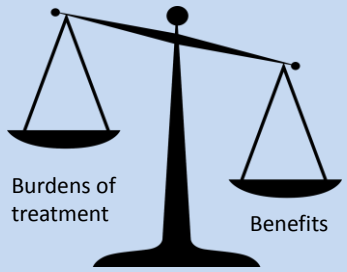
If patient left **instructions** addressing situation, follow those instructions

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

Unbefriended

Unrepresented

Adult orphan

Patient w/o proxy

Incapacitated & alone

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

3

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

5

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

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

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

3 - 4%

U.S. nursing home population

CDC Monitoring the Nation's Health

SAFER • HEALTHIER • PEOPLE™

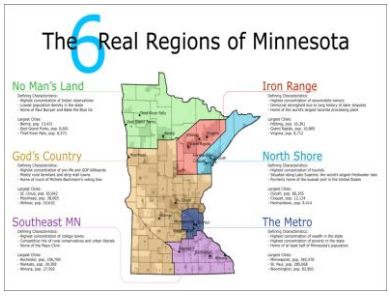
Long-Term Care Providers and Services Users in the United States: Data From the National Study of Long-Term Care Providers, 2013–2014

1.4 million

Vital and Health Statistics Series 3, Number 38 February 2016

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

> 56,000 in USA



~1377

Extrapolated
5.5m / 319m = 1.7%

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

WINSOR C. SCHMIDT*

300 to 700

Trust Fund is gratefully acknowledged. This Article is based on a Final Report submitted to the Human Services Committee, North Dakota Legislature: Winsor Schmidt, Study of Guardianship Services for Vulnerable Adults in North Dakota (May 30, 2012).

Royal College of Physicians | Marie Curie
Care and support through terminal illness

End of Life Care Audit – Dying in Hospital

National report for England 2016

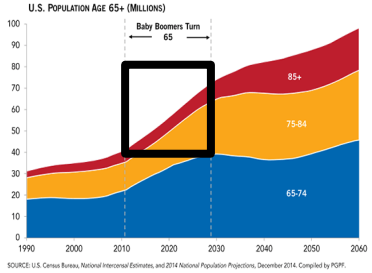
Table 14

	National audit (n=9302)	
3.4. Is there documented evidence that the cardiopulmonary resuscitation (CPR) decision by a senior doctor was 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

*81% if the 'NO BUTs' are excluded from the denominator

Growing problem

1



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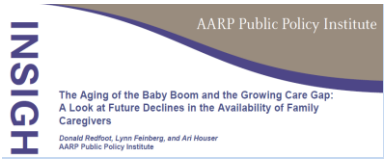
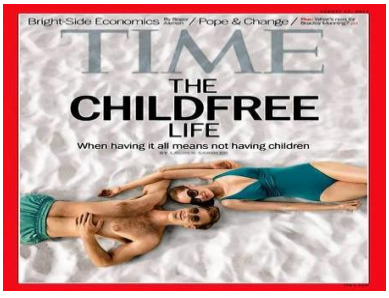
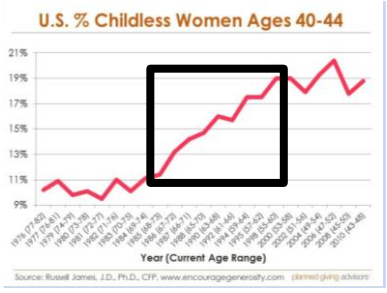


10,000,000
Boomers live **alone**

3





Key Findings

- The biggest fear (92 respondents) was having no one to speak up for them or act in their best interests when they could no longer do so for themselves

Ageing without Children survey results 2015

4

Others "have" family members

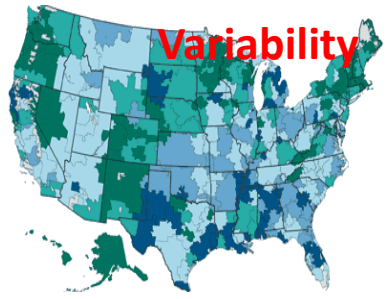
No **contact** (e.g. LGBT, homeless, criminal)

Surrogates 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

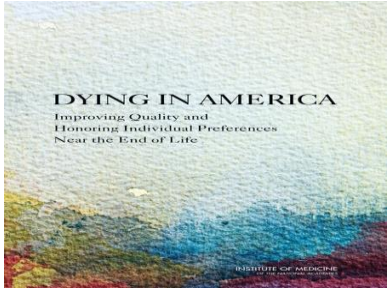
1

No treatment

Wait until emergency (implied consent)

Longer period suffering

Increases risks



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"

Under-treatment

2

Over-treatment

Physician acts **without** consent

Most common approach

Fear of liability

Fear of regulatory sanctions

Bias

COI

Careless

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

WINSOR C. SCHMIDT*

"unimaginably helpless"

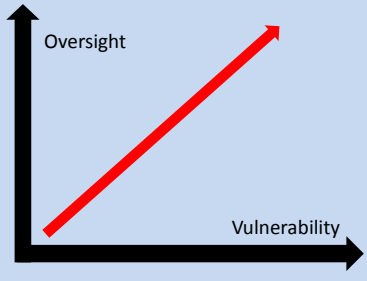
POSITION STATEMENT

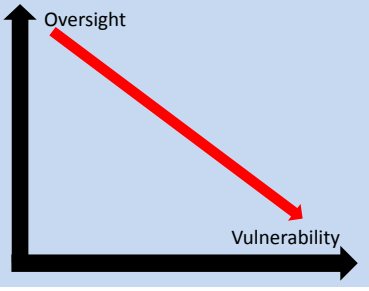
Making Treatment Decisions for Incapacitated Older Adults Without Advance Directives

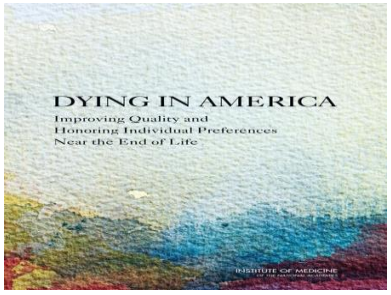
*AGS Ethics Committee**

"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

23-06.5-04. 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; or
4. A nonrelative of the principal who is an employee of the principal's long-term care services provider.

30.1-28-11. (5-311) 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

3

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

CANHR
CALIFORNIA ADVOCATES FOR NURSING HOME REFORM

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)

Unit 7 of 7

Solutions

In addition to new **laws**

POSITION STATEMENT

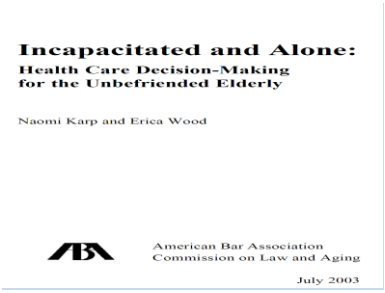
Making Treatment Decisions for Incapacitated Older Adults Without Advance Directives

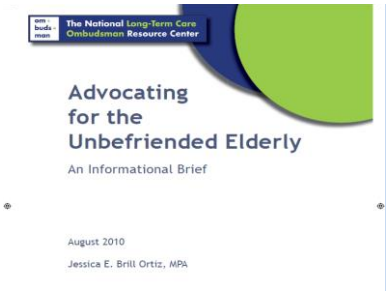
AGS Ethics Committee

JAGS 44:986–987, 1996
© 1996 by the American Geriatrics Society

BACKGROUND

Geriatric practitioners are often faced with the problem of making treatment decisions for patients who lack deci- patient's wishes or value systems. In some cases, surviving family members have only remote knowledge of the patient's values, or are estranged, whereas close friends or others





2016

2017

Prevention

1

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

POSITION STATEMENT

Making Treatment Decisions for Incapacitated Older Adults Without Advance Directives

AGS Ethics Committee

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.

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.

3

Assess capacity more carefully

Not all or nothing

Patient may lack capacity for complex decisions

But **have** capacity to appoint a surrogate

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.

If you need a SDM

Mechanisms **short** of guardianship

Too expensive

Too slow

POSITION STATEMENT

Making Treatment Decisions for Incapacitated Older Adults Without Advance Directives

AGS Ethics Committee

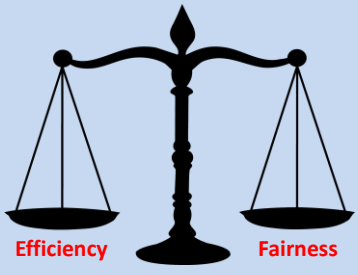
POSITION 3

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

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

(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

Conclusion



Accessible, quick, convenient, cost-effective

Expertise, neutrality, careful deliberation

References

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