Minnesota Surrogate Decision Making
MN Fall Aging Conference (Oct. 26, 2017)

Thank you

Legal

Medical ethics

Roadmap

Decision making capacity

Making decisions when patient lacks capacity

3 preferred mechanisms

3 other mechanisms
Capacity

If decision not impaired by cognitive or volitional defect, providers must respect decision. Patient has capacity to make decision at hand. Patient decides herself.

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

Clinicians must rebut the presumption

No need to prove capacity

Must prove incapacity

Sometimes obvious

Advanced dementia

PVS
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

Choose dinner

Still have capacity to **appoint** surrogate
May **fluctuate** over time

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

**Restore** capacity if possible

Patients often **lack** capacity

Not **yet** acquired (minors)
Never had (mental disability)

Had but lost (dementia...)

Most common

Adults who once had but later lost capacity

Can no longer make own decisions

Mechanisms

3 preferred

Advance directive
POLST
Agent / DPAHC

3 other
Hear from patient herself

Best DM for you is you

Obstacle 1

Not completed

28%

AARP

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

Views on End-of-Life Medical Treatments
Growing Minority of Americans Say Doctors Should Do Everything Possible to Keep Patients Alive

99497
99498

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

Obstacle 2: Not found

Obstacle 3

Fail to make & distribute copies
- Primary agent
- Alternate agents
- Family members
- PCP
- Attorney
- Clergy
- Online registry

Complete ≠ Have

Even if completed & available

Not clear

if ___, then ___
If “Reasonable expectation of recovery”?

Then “No ventilator” Ever Even if temporary

Vague Ambiguous Limits

Enough The Failure of the Living Will

In pursuit of the dream that patient autonomy would extend beyond the span of competence, living wills have passed from controversy to conventional wisdom. To publicly promulgate policy, but the policy has not produced results, and should be abandoned.
Controlling Deaths: The False Promise of Advance Directives

2 parts to AD

Instruct
Appoint

Hear from the patient **herself**

**BUT**

Advance directives not self-executing

Need a SDM

Instruct
Appoint

“Agent”
“DPAHC”
10/26/2017

1st choice – patient picks herself

BUT

Usually in an advance directive

Not completed
Not found

Still need a SDM

Overcome some AD limitations by supplementing AD

POLST

Provider
Orders
Life
Sustaining
Treatment

What is POLST
For whom

POLST supplements AD
Does not replace

Also: others who want to define care

POLST primarily for those expected to die in next year

Terminal illness
Advanced chronic progressive illness
Frailty

POLST benefits
EMS will follow POLST but not AD

Provider Orders
Life Sustaining Treatment

No need to “interpret” advance directive

Immediately actionable

More informed

Single page
No need to “translate” into orders

Easy to follow

Better honored

Can follow **Will** follow

Portable

Updatable

POLST does **not** expire
POLST can be revised or revoked anytime

Review with change in condition or location

Can be completed by surrogate, if patient lacks capacity

70% patient
30% surrogate

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

“Surrogate” “Proxy”

Almost all states specify a sequence

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

More relatives

ND list is longer than most
9 categories deep
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.

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.

BUT

No authoritative list in Minnesota

Custom & practice

MMA Policies
2015

(reflects policies adopted through April 30, 2015)

24A.22 Decisions to Forgo or Limit Life-Sustaining Treatment for Patients Lacking Decision-Making Capacity

The MMA endorses the AHA Council on Ethical and Judicial Affairs recommendations adopted at the 1991 AHA Annual Meeting as follows:
"Without an advance directive that designates a proxy..."

"patient's family should become the surrogate..."

"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."

Judicially endorsed

In position 2, it should not be assumed that the absence of traditional surrogates (most 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.
1. Plaintiffs are appropriate surrogate decision makers for all health care decisions for their son, and they are not required to petition for or be appointed guardians or conservators in order to continue making all health care decisions for their son.

No default surrogate statute

Minneapolis not alone

De facto flexibility

BUT

Some providers refuse to recognize family

NJ  IN

NY  NJ
Still need a SDM

Guardian

3rd choice – After agent & surrogate

Ask **court** to appoint SDM

Last resort

Not sufficiently responsive

3 SDM types

<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>
</tr>
<tr>
<td>Legislature</td>
<td>Surrogate Proxy</td>
</tr>
<tr>
<td>Court</td>
<td>Guardian Conservator</td>
</tr>
</tbody>
</table>

How does SDM decide?
Any type of SDM can usually make any decision patient could have made

Minn. Stat. 145C.07(3)
Health care agent must “act in the best interests . . . considering . . . the principal’s personal values to the extent known”

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

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

~ 60% accuracy
More aggressive treatment

"surrogate’s decision . . . almost always accepted"

Advanced dementia
End stage kidney disease
Chronic respiratory failure

State of Minnesota
District Court—Probate Court Division
County of Hennepin
Fourth Judicial District

Al Barnes

Abel Tello
aggressive treatment is unethical & painful
CMO
BUT

Agent: wife Lana

Clinicians should not follow “bad” surrogates

Beyond what is identified above, Mrs. Barnes has not acted in the best interest of Mr. Barnes and has failed to appropriately advocate for Mr. Barnes. Mrs. Barnes continues to demand unnecessary, inappropriate, and in some cases harmful, testing and treatment for Mr. Barnes. Mrs. Barnes

Recap

We looked at 5 SDM mechanisms

Advance directive POLST Agent / DPAHC
Default surrogate Guardianship

Unrepresented

“highly vulnerable”
“most vulnerable”

Increasingly common situation

Minnesota 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

American Bar Association Commission on Law and Aging

July 2003
Who are unbefriended patients?

Definition
1. Lack capacity
2. No available, applicable AD or POLST
3. 3 conditions
No reasonably available authorized surrogate

Nobody to consent to treatment

Big problem

Hospital estimates

16% ICU admits

5% ICU deaths

> 25,000
LTC estimates

Incapacitated and Alone:
Health Care Decision-Making for the Unbefriended Elderly
Naomi Reep and Naomi Wood

American Bar Association
Commission on Law and Aging
July 2013

3 - 4%
U.S. nursing home population

1.4 million

Extrapolate
5.5 / 320
1.7%

> 56,000

1400

Not far off
GUARDIANSHIP FOR VULNERABLE ADULTS IN NORTH DAKOTA: RECOMMENDATIONS REGARDING UNMET NEEDS, STATUTORY EFFICACY, AND COST EFFECTIVENESS

300 to 700

Growing problem

THE COMMISSION ON END OF LIFE CARE
Final Report
January 2002

This Commission on End of Life Care was created by the Minnesota Partnership to Improve End of Life Care and the Minnesota Department of Health.

INSIGHT
AARP Public Policy Institute

10,000,000
Boomers live alone

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

Sondra Feldman, Lynn Reinberg, and Ali Hooser
AARP Public Policy Institute

Just 4 causal factors

1

2

Outlived
Lost touch
3

Others “have” family members

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

Family member also lacks capacity

Able but unwilling

Risks & Harms
Cannot advocate for self

Have no substitute advocate

“unimaginably helpless”

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

“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 . . . consideration of patient preferences or best interests”

No discharge to appropriate setting
Challenges

Default surrogate law for MN

Mechanism for unbefriended

SDM help avoid advanced dementia

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