Lessons from Seville: Identifying and Reducing Inappropriate End-of-Life Treatment in New Jersey

Thaddeus Mason Pope, J.D., Ph.D.
Z. Stanley Stys Memorial Lecture
Princeton University Medical Center
May 10, 2011

Delighted
Honored

Z. Stanley Stys
Danuta Buzdygań

April 18, 1955
Princeton, NJ
I want to go when I want. It is tasteless to prolong life artificially.

I have done my share, it is time to go. I will do it elegantly.

CPR
Dialysis
Mech. ventilation
ICUs
More technology

Used more
Value = \frac{Quality}{Cost}

71\%: \text{“More important to enhance the quality of life for seriously ill patients, even if it means a shorter life.”}

\textit{National Journal (Mar. 2011)}
<table>
<thead>
<tr>
<th>Question and Responses</th>
<th>Public, % (n=1006)</th>
<th>Professionals, % (n=774)</th>
</tr>
</thead>
<tbody>
<tr>
<td>If doctors believe there is no hope of recovery, which would you prefer?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Life-sustaining treatments should be stopped and should focus on comfort</td>
<td>72.8</td>
<td>92.6</td>
</tr>
<tr>
<td>All efforts should continue</td>
<td>20.6</td>
<td>2.5</td>
</tr>
</tbody>
</table>

### Dying at Home: Wishes vs. Reality

<table>
<thead>
<tr>
<th>Percent</th>
<th>Wish To Die At Home</th>
<th>Die At Home</th>
</tr>
</thead>
<tbody>
<tr>
<td>67</td>
<td></td>
<td>24</td>
</tr>
</tbody>
</table>

Harm to family
Emotional
Economic
Harm to others

- Limited ICU beds
- ER boarding
- Antibiotic resistance
- Moral distress
Why
How to fix

Patients
Surrogates
Providers
Payers

Patient Problem
EOL discussion
less aggressive medicine

Arch Intern Med. 2009;169(3):480-488
Disussed EOL Care Preferences
With Physician

<table>
<thead>
<tr>
<th>Variable</th>
<th>Yes (n=100)</th>
<th>No (n=196)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical care received during the last week of life, No. (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intensive care unit stay</td>
<td>2 (2.0)</td>
<td>10 (14.3)</td>
</tr>
<tr>
<td>Ventilator use</td>
<td>1 (1.0)</td>
<td>10 (14.5)</td>
</tr>
<tr>
<td>Resuscitation</td>
<td>1 (1.0)</td>
<td>6 (8.6)</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>4 (4.0)</td>
<td>7 (10.0)</td>
</tr>
<tr>
<td>Inpatient hospice stay ≥ 1 wk</td>
<td>8 (8.0)</td>
<td>5 (7.1)</td>
</tr>
<tr>
<td>Outpatient hospice stay ≥ 1 wk</td>
<td>58 (58.0)</td>
<td>40 (51.5)</td>
</tr>
<tr>
<td>Place of death, No. (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intensive care unit</td>
<td>2 (2.0)</td>
<td>9 (13.2)</td>
</tr>
<tr>
<td>Hospital</td>
<td>16 (16.0)</td>
<td>16 (26.9)</td>
</tr>
<tr>
<td>Inpatient hospice</td>
<td>5 (5.0)</td>
<td>3 (4.4)</td>
</tr>
<tr>
<td>Home</td>
<td>47 (47.0)</td>
<td>38 (55.0)</td>
</tr>
</tbody>
</table>

EOL discussion
Earlier hospice referral
Better patient QOL
Better family bereavement
65-76% of physicians whose patients have advance directives do not know they exist

**Enough**

The Failure of the Living Will

*by Angela Fagglin and Carl E. Schneider*

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

---

**Trigger terms vague**

“Reasonable expectation of recovery”

75% 51%

25% 10%

Plus: prognosis uncertain
Preferences vague

“No ventilator”

Ever

Even if temporary

More technology is the default

Patient must opt out

Patient Solution
More ACP
Better documentation
Equalized safeguards

Prompt Providers

1991
Enforce PSDA
Voluntary Advance Care Planning

Blumenauer
H.R. 3200
Sec. 1233

Today I was told I was too old...
I was canceled
Rationed healthcare
For the good of the country

Red Flag
This product is toxic

Seniors check in...
But they don’t check out!
PPACA silent on ACP. But does cover annual wellness visits.

Section 4103

DHHS: “Notice of Proposed Rulemaking: Physician Fee Schedule” (July 2010)

Final Rule (Nov. 2010)

Defined “VACP” as element of annual wellness visit
Lie of the Year: “Death Panels”

A “quiet” victory

“The longer this goes unnoticed, the better our chances of keeping it.”

Jan. 2011: Rescind VACP

“We did not have an opportunity to consider... the wide range of views... held by a broad range of stakeholders”
One Hundred Tenth Congress
of the
United States of America

AT THE SECOND SESSION

(1) In general.—Section 1861(e)(2)(D) of the Social Security Act (42 U.S.C. 1395x(e)(2)(D)) is amended—

(a) by adding to the end of the section the following new paragraph:

“(3) For purposes of paragraph (1), the term ‘end-of-life planning’ means verbal or written information regarding—

(A) an individual’s ability to prepare an advance directive in the event that an injury or illness causes the individual to be unable to make health care decisions; and

(B) whether or not the physician is willing to follow the individual’s wishes as expressed in an advance directive.”

112th CONGRESS
1st SESSION

H. R. 1589

To amend the Social Security Act to provide for coverage of voluntary advance care planning consultation under Medicare and Medicaid, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES
Apr. 15, 2011

SECTION 1. SHORT TITLE; FINDINGS; TABLE OF CONTENTS.

(a) Short Title.—This Act may be cited as the “Personalize Your Care Act of 2011”.
Derecho a la información asistencial

Deberes respecto a la información clínica
Content agnostic

Make AD available
Registries
Organ donation
NOK

Make AD effective

FIVE WISHES
compassion & choices
**POLST**

Closes gap between what people *want* and what they *get*.

**Actionable orders**

More likely honored

No need to “translate”
Portable

Travels with the patient in all treatment settings

- Home
- LTC
- Hospital
- EMS

Surrogate Problem
No capacity
No instructions

Surrogate decides

Surrogate must comply
Written instructions
Values & preferences
Best interests

66% accurate
50% = pure chance
Even lower
when most needed:
intermediate zones
More aggressive treatment

Futility

Surrogate Solution
Educate
Mediate
Replace
Override

Educate

Guide For Healthcare Agents & Surrogate Decision-Makers
Making decisions for patients who can't speak for themselves
Statement to Agent

Agent’s Duties

When you accept the authority granted under this power of attorney, a special legal relationship is created between you and the Principal. This relationship imposes upon you legal duties that continue until you resign or the power of attorney is terminated or revoked. You must:

Agent’s Certification

1. ______________________, have read the attached durable power of attorney and the foregoing statement, and I am the person identified as the Agent for the Principal. To the best of my knowledge, this power has not been revoked, I hereby

Agent Signature ______________________ Date ______________________
Earnest attempts . . . deliberate over and negotiate prior understandings . . .

Joint decision-making should occur . . . maximum extent possible.

Attempts . . . negotiate . . . reach resolution . . . , with the assistance of consultants as appropriate.

Involvement of . . . ethics committee . . . if . . . irresolvable.
Early famous failure
Helga Wanglie
(Minn. 1991)

85-year-old
End-stage kidney failure
Chronic respiratory failure
Dementia

Lana Barnes
SDM
“Continue”
Court: “Your own personal issues are “impacting your decisions”

“Refocus your assessment”
Providers cannot show deviation

Surrogates often faithful

57%: God could heal patient even if physicians had pronounced further efforts futile
20%: “More important to prolong life.”

National Journal (Mar. 2011)
Archives Surgery (Aug. 2008)
Pew Ch. (Nov. 2005)

If cannot replace surrogate, then provide the treatment

Capacity and Consent Board
Dispute resolution mechanisms for intractable cases in which surrogates are “irreplaceable”

Override

Physicians usually cave-in to surrogate demands
“Remove the __, and I will sue you.”

 why they follow the instructions of SDMs instead of doing what they feel is appropriate, almost all cited a lack of legal support.”

DOCTOR SURVEY

<table>
<thead>
<tr>
<th>Action</th>
<th>% ordered for defensive reasons</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital admissions</td>
<td>13.0%</td>
</tr>
<tr>
<td>Lab tests</td>
<td>17.9%</td>
</tr>
<tr>
<td>X-rays</td>
<td>21.9%</td>
</tr>
<tr>
<td>Ultrasound studies</td>
<td>24.0%</td>
</tr>
<tr>
<td>MRI studies</td>
<td>27.4%</td>
</tr>
<tr>
<td>CT scans</td>
<td>27.6%</td>
</tr>
<tr>
<td>Specialty referrals</td>
<td>28.4%</td>
</tr>
</tbody>
</table>
Providers have won almost **every single** damages case brought after unilateral withholding.

HCP exposure = **IIED**
- Secretive
- Insensitive
- Outrageous

Risk > 0
73yo male
PVS
COPD
End-stage renal disease
Hypertensive cardiovascular disease

Stage 4
decubitus ulcers
Osteomyelitis
Diabetes
Parchment-like skin

“The only organ that’s functioning really is his heart.”
“It all seems to be ineffective. It’s not getting us anywhere.”
“We’re allowing the man to lay in bed and really deteriorate.”
Intramural process
   No consensus

Unilateral withdrawal
   DNR order written
   Dialysis port removed

January 2009
   Jacqueline files
   Court issues TRO

February 2009
   Evidentiary hearings
   Medical experts
   Family members
March 2009
Permanent injunction

April 2010
NJHA
MSNJ
NJP
GNYHA
CHPNJ
Disability coalition
Jewish coalition
Pope

August 2010
Appeal dismissed
No guidance
No clarity
You can stop LSMT for any reason if your hospital ethics committee agrees.
Tex. H&S Code 166.046

48hr notice
Ethics committee meeting
Written decision
10 days
No judicial review

Tex. H&S Code 166.045

[N]ot civilly or criminally liable or subject to review or disciplinary action . . . complied with . . . procedures
Intractable value conflict

Pure process

If process is all you have, it must have integrity and fairness
Notice

Independent, neutral decision-maker

Judicial review
<table>
<thead>
<tr>
<th>P/S:</th>
<th>D: Palliative</th>
<th>D: Curative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative</td>
<td>OK</td>
<td>OK</td>
</tr>
<tr>
<td>Curative</td>
<td>Futility</td>
<td>OK</td>
</tr>
</tbody>
</table>

EOL communication

Defensive medicine

Offensive medicine
Table 3—Factors Associated With Patient/Surrogate Preference for Full Code Status

<table>
<thead>
<tr>
<th>Factor</th>
<th>Percentage Desiring Full Code Status</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Estimated chance of survival following CPR, %</td>
<td>0.012</td>
<td></td>
</tr>
<tr>
<td>0-25</td>
<td>35.3</td>
<td></td>
</tr>
<tr>
<td>26-50</td>
<td>64.7</td>
<td></td>
</tr>
<tr>
<td>51-75</td>
<td>82.9</td>
<td></td>
</tr>
<tr>
<td>76-100</td>
<td>92.7</td>
<td></td>
</tr>
</tbody>
</table>
"improve life expectancy by 50%"

Defensive Medicine

HEALTH AFFAIRS 29, NO. 9 (2010): 1585-1592

I order some tests or consultations simply to avoid the appearance of malpractice

Feel pressured in my day-to-day practice by the threat of malpractice litigation
<table>
<thead>
<tr>
<th>Factor</th>
<th>Extremely or Very Important</th>
<th>Most Important of All Factors Listed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient’s prognosis</td>
<td>98.5</td>
<td>12.0</td>
</tr>
<tr>
<td>What was best for the patient overall</td>
<td>98.1</td>
<td>33.2</td>
</tr>
<tr>
<td>Respecting the patient as a person</td>
<td>96.6</td>
<td>5.4</td>
</tr>
<tr>
<td>Patient’s pain and suffering</td>
<td>94.6</td>
<td>12.5</td>
</tr>
<tr>
<td>What the patient would have wanted you to do</td>
<td>81.8</td>
<td>25.4</td>
</tr>
<tr>
<td>Providing the standard of care</td>
<td>81.5</td>
<td>2.2</td>
</tr>
<tr>
<td>Respecting the wishes of the family or surrogates</td>
<td>80.9</td>
<td>3.3</td>
</tr>
<tr>
<td>Following the law</td>
<td>68.6</td>
<td>1.1</td>
</tr>
<tr>
<td>The burden on the family</td>
<td>44.8</td>
<td>0</td>
</tr>
<tr>
<td>Religious beliefs of the patient</td>
<td>35.3</td>
<td>0</td>
</tr>
<tr>
<td>Religious beliefs of the family or surrogates</td>
<td>28.6</td>
<td>0</td>
</tr>
<tr>
<td>Cost to society of caring for the patient</td>
<td>14.2</td>
<td>0</td>
</tr>
<tr>
<td>Physician’s religious beliefs</td>
<td>10.7</td>
<td>0</td>
</tr>
<tr>
<td>Concerns about paying for medical care</td>
<td>9.3</td>
<td>0</td>
</tr>
<tr>
<td>Concern that the surrogates might sue</td>
<td>8.4</td>
<td>1.1</td>
</tr>
</tbody>
</table>

Would you recommend or give life-sustaining therapy when you judged it futile?

**Yes 23.6%**

MedScape (Nov. 2010)
Table 4. Responses Regarding Demanding Care and Goals of Care for Those in a Persistent Vegetative State

<table>
<thead>
<tr>
<th>Question and Responses</th>
<th>Public, % (n=1006)</th>
<th>Professionals, % (n=774)</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do patients have the right to demand care that doctors think will not help?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>72.4</td>
<td>44.9</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>No</td>
<td>20.2</td>
<td>44.8</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>
Limited effectiveness
Side effects
Options
El médico limitará el esfuerzo terapéutico, cuando la situación clínica lo aconseje, evitando la obstinación terapéutica.
Hargett v. Vitas

Strachan v. John F. Kennedy Memorial Hospital (N.J. 1988)

False Claims Act
Autonomy
Beneficence
Nonmaleficence
Justice