Shared Decision Making & Advance Care Planning: Using Decision Aids to Improve Patient Safety

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Disclosures

I have no conflict of interest to report.

I will not discuss any off-label use of any product.

I have received no commercial support for this presentation.

Objectives

1. Identify the limitations of traditional advance care planning.

2. Distinguish informed consent from shared decision-making.

3. Describe the advantages of patient decision aids (PDAs) over traditional informed consent.

4. State the importance of shared decision making for advance care planning.

Time
8:45 - 9:45
Break: 9:45 – 10:00

Core thesis

Powerful

Value of PDAs like videos

Why use more PDAs in ACP
2014
ACP PDA now

Roadmap

4
ACP obstacles
Promise of PDAs

PDAs for ACP

PDA certification

ACP Obstacles

Breakout Sessions by Topic

FACE Pre-Conference
This pre-conference workshop will bring together interdisciplinary staff from ACE organizations.
Throughout the day for the purpose of:
- Identifying potential ACP training programs
- Education in Advance Care Planning
- Developing ACP Implementation
- Building community and foster new connections

Ethics:
- Competency, Capacity, and Consenting: On My Life!
- Just One Word: Simple Tools for Healthcare Communication
- Impacting Outcomes for Patients and Caregivers Through Care Coordination
- Ethical Issues in ACP
- The Gray Areas of ACP: The Collision of Life Versus Medicine

Session-Specific Content:
- "Women's Influence of Integrating Advance Care Planning for Those With Incest/Assault"
- "Embracing Food and Water, and Overcoming Barriers to ACP: Promoting Health-Advance Directives" (for care providers)
- "Youth and Parent Health-Advance Directives" (for families)

Conversation Skills:
- ACP Conversations with Your Loved One
- "Death, Dying, and Delirium: Engaging the Cultural Conversation in Advance Care Planning"
- "Michigan Physician Orders for Scope of Treatment (M-POST) New Form"
- "Dying to talk about it..."

Face, Culture, and Self- Care:
The Impact of ACP in the Health Care Setting: Spirituality in the ACP process
- "Care of the Acute / Vacuum Patient"
- "Shaping Heart Building Resilience in Your Practice Training"
- "ACP in the Community: The Experience of ACP Programs on What It Takes to Engage Others"

Post-Conference Workshop: Art & Design of Successful ACP Implementation
This workshop will allow attendees through designing an ACP program specific to your individual setting. At the end of the workshop, attendees will be able to:
- Describe the current state and address regulatory issues related to advance directives, treatment decisions, standing orders, and codes status in various healthcare settings
- Design tools with identification of needed partnerships for successful implementation of ACP programs and M-POST
- Employ effective patient and family engagement techniques, and consent challenges of ACP in rural healthcare settings and communities
- Identify at least three tools and or templates that would be adaptable to ACP and M-POST in present work setting
Not completed
Not found
Not understood
Not followed
Not i-actionable

37%
Systematic review of 150 studies (800,000 people 2011 to 2016 Health Aff 2017 36(7):1244

70%
Older Americans

Even higher

NCHS Data Brief No. 54 January 2011
Higher still

BUT

Not found

Even if completed

76% of physicians whose patients have ADs do not know they exist
Completed ≠ Have

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

Not enough to “write it down”
Must be available

Only 1/3 advance directives used

Sen. Jim Marleau

AD or POLST registry

Home
Welcome to the Peace of Mind Registry.
Someday, an illness or injury may leave you unable to make important health care decisions for yourself. To prepare for that possibility, you may want to write down your wishes in an advance directive. An advance directive can help ensure your wishes are honored in the future.
Preparing an advance directive is voluntary - no one requires...
Who has an AD

Who put their AD in registry

BUT

Even if completed & found

Not understood
Not clear if ___, then ____

If triggering condition

“Reasonable expectation of recovery” 75% 51% 25% 10%
Then

“No ventilator”

Ever?
Even if temporary

Vague
Ambiguous

Limits

*Enough: The Failure of the Living Will*

By Angela Fagerlin and Carl E. Schneider

*Hastings Center Report*
Even worse

TRIAD research

The Realistic Interpretation of Advance Directives

TRIAD IX: Can a Patient Testimonial Safely Help Ensure Prehospital Appropriate Critical Versus End-of-Life Care?

Mizrahi, Ferdinando Pa/CPEP, FAEM; Carmissa, Christopher DO; Cooney, Timothy E. MS; Jolosa, Krista DO; Terman, Stanley A. PhD, MD
Journal of Patient Safety: Post Author Corrections: June 16, 2017
Advance directive

DNR

Do Not Treat

DNR

Who has seen this

TRIAD finds patient safety problems

Also identifies solutions
TRIAD VIII: Nationwide Multicenter Evaluation to Determine Whether Patient Video Testimonials Can Safely Help Ensure Appropriate Critical Versus End-of-Life Care

“adding a video testimonial/message . . . significant . . . achieving interpretive consensus”

More obstacles

Even if completed found, and understood

Not followed

Compliance with Advance Directives
Holly Fernandez Lynch J.D., M.Be., Michele Mathes J.D. & Nadia N. Sawicki J.D., M.Be.

*The Journal of Legal Medicine, 29:133–178*
The New York Times

The Patients Were Saved. That’s Why the Families Are Suing.

Paula Span

Doctors Hospital Augusta v. Alicea (Ga. 2016)

$1,000,000

(plus appeal to SCOGA)

Last obstacle
Even if completed, found, understood, and followed

Not i-actionable

e.g. EMS cannot follow

Must “translate” ADs to orders

MI-POST

HB 4170 (Pub. Act 154)
Immediately actionable

Recap

5 obstacles

Not completed
Not found
Not understood
Not followed
Not i-actionable

Working on overcoming these obstacles

One more
Comparatively neglected

Not informed

Know this guy?

Treatment not clinically indicated
Harry Persaud – sentenced 20 years cardiac stents when no blockage.

Breast surgeon Ian Paterson jailed 15 years for needless operations.

Unwanted medical treatment

No patient would want

Indicated

2nd type UMT
Clinical basis for treatment

Treatment not preference indicated

Clinically Indicated

Want

No want
Reasonable patient might want this

But . . . this patient does not

Too little to help patients avoid this UMT

Medical consent
Bad Processes
Delivery not receipt

Sign posted, not seen

Informed consent not done with patients

It is done to patients

“Consent the patient!”
Like other consumer disclosures

Disclosure was supposed to be a means to the goal of understanding

Today, disclosure is the goal

1972

Doctrine of informed consent

Justice Mosk
“lengthy polysyllabic discourse”

2018

“lengthy polysyllabic discourse”

Still
Stalled 50 years

Medical consent
Bad Outcomes

Not only bad processes

Some patients totally uninformed

Only 31% advanced cancer had EOL discussions

Health Care Costs in the Last Week of Life

Association with Pain, Fear, EOL Care, and Prognosis

Background:

Patient physical symptoms, such as pain, are associated with lower quality of end-of-life care. Patient physicians discuss EOL care, are associated with lower rates of intensive interventions.

Methods:

1274 patients with advanced cancer in the last week of life were included in this study. Costs for intensive care unit and hospital stay, hospice care, and last medical procedure were calculated and compared with the costs for patients with advanced cancer. Costs were adjusted for predictors of quality of end-of-life care.

Results:

Of 1274 participants, 589 (46.1%) reported EOL discussions at baseline. After propensity score matching, the remaining 435 patients did not differ in socio-

health status characteristics, namely, sex, age, and location of the study. In the last week of life, patients who had end-of-life discussions had lower costs, and the length of hospital stay and hospice care, and the last medical procedure were lower. Patients who had end-of-life discussions had lower costs and a higher level of satisfaction with quality of end-of-life care. (Fisher exact test, *p* = 0.0001).

Higher costs were associated with worse quality of end-of-life care. Higher costs were associated with worse quality of end-of-life care. (Fisher exact test, *p* = 0.0001).

Only 31% advanced cancer had EOL discussions.
Only 12% of clinicians discuss with heart failure patients.

Language Services In Hospitals, Health Aff (Aug 2016)

Ineffective disclosure

Whether

How
1000 audiotaped encounters

9%

The role of informed consent in patient complaints: Reducing hidden health system costs and improving patient engagement through shared decision making

“potential risk of harm . . . included”
“but . . . not clearly understood”

“Risk of dental injury . . . disclosed”

“not appreciate implications . . . appearance . . . (front teeth). . .”

“Nerve injury . . . disclosed”

“not understand . . . manifest as pain or weakness in an extremity”

Who’s been out to dinner in past few weeks?
Too much
Too fast
Too complex

Also in
medicine

Also in
ACP

Older Adults More Likely to Discuss
Advance Care Plans With an
Attorney Than With a Physician

Mercedes Bern-Klug, PhD
and Elizabeth A. Byram, MSW
Attorney 38%  
Physician 23%

Naming agent  
Attorney  
=  
Physician

Less sure about goals of care

POLST
Problems

Completion of a POST form requires shared decision making between the health care professional . . . and the patient, or . . . representative.

“must be a discussion of . . . diagnosis and prognosis . . . available treatment options”
BUT

Architects & leaders

2 worrying reports (summer 2018)

“health plans . . . measure the frequency of POLST form completion”
“few patients or their family members recalled being counselled on . . . POLST”

Signing a POLST form without meaningful discussion

Providing incentives for completing more POLST forms.
ACP suffers same patient understanding problems

ACP benefit same solutions

Solution Problems

Patient decision aids
During encounter

Present options clearly & graphically

THAI CUISINE

SOUP
1. ❖ Tom Yum
   Chicken or Vegetable $2.50 • $4.95
   Seafood or Shrimp $5.95
2. ❖ Tom Ka
   Chicken or Vegetable $2.50 • $4.95
   Seafood or Shrimp $5.95

CURRY ENTREES
- Chicken, Vegetable or Tofu $9.95
- Green Curry
  Green curry made of coconut milk, pepper, basil, and eggplant
- Red Curry
  Red curry made of coconut milk, pepper, basil, and eggplant
- Panang Curry
  Panang curry made of coconut milk, string beans, chili pepper
- Yellow Curry
  Yellow curry made of coconut milk, peppers, and onion
- Massaman Curry
  Massaman curry made of coconut milk, potatoes and onions

NOODLES
- $6.95
  Shrimp or Beef $6.95 / Chicken or Vegetables $6.95
- Pad Thai
  Prepared rice noodles with eggs, bean sprouts, seaweed and fried peanuts
Do they work?

Yes

Robust evidence shows PDAs are highly effective

> 130 RCTs

30,000 patients

50 conditions
Improved knowledge

More accurate expectations

Lower decisional conflict
  (less uncertainty)

More value congruent choice

Great evidence
ACP PDAs

What is the problem?

Too few clinicians use PDAs
Australia  Canada  Denmark  Germany  Netherlands
Norway  Taiwan  UK  USA

“More work has been done on SDM in the US than in any other country.”

BUT

“not incorporated into mainstream care”

So:

Move PDAs from research to practice
From lab to clinic

Payment Tools

Agency in charge is CMS

Other insurers

No PDA

PDA use = “condition for payment”
Medicare only pays "medically necessary"

"Medically necessity" not purely clinical determination

Unwanted
Not med. necc.

Require PDA as COP

2015  2018

3 examples
Screening for Lung Cancer with Low Dose Computed Tomography

30 pack year smoking history

Before CT scan

“must receive . . . SDM visit”
“include . . . one or more decision aids”

Is Lung Cancer Screening Right for Me?
A decision aid for people considering lung cancer screening with low-dose computed tomography

If you have smoked for many years, you may want to think about screening (testing) for lung cancer with low-dose computed tomography (LDCT). It's a decision you should think about the

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<table>
<thead>
<tr>
<th></th>
<th>Favor Screening</th>
<th>Favor No Screening</th>
</tr>
</thead>
<tbody>
<tr>
<td>How important is it to know lung cancer early when it may be more easily treated?</td>
<td><img src="https://via.placeholder.com/15" alt="" /></td>
<td><img src="https://via.placeholder.com/15" alt="" /></td>
</tr>
<tr>
<td>Having a false test if you have a positive screening test?</td>
<td><img src="https://via.placeholder.com/15" alt="" /></td>
<td><img src="https://via.placeholder.com/15" alt="" /></td>
</tr>
</tbody>
</table>

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2
Implantable Cardioverter Defibrillators

Before implantation

“formal SDM encounter must occur”

“evidence-based decision tool”

Delivers electric shock to restore normal heartbeat
Percutaneous Left Atrial Appendage Closure Therapy

LAA = source for blood clots that can cause strokes

Warfarin NA (Coumadin)

Thin blood with anticoagulant medication

Mfg. By: Bristol-Myers Squibb Company
Garden City, NY
Repackaged by Agenera Pharma
Cookeville, TN 38506

Warfarin NA (Coumadin) 2mg 90 Tablets

THERE'S AN ALTERNATIVE TO WARFARIN
FOR PEOPLE WHO NEED ONE. IT'S CALLED WATCHMAN™.
Before implantation

“formal SDM interaction”

evidence-based decision tool”

ACP PDAs

Help patients envision future circumstances

No intubation

Verbal 53% Video 80%

Circulation 134:52
Adv. dementia comfort care

<table>
<thead>
<tr>
<th>Verbal</th>
<th>Video</th>
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<tr>
<td>50%</td>
<td>89%</td>
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Adv. cancer comfort care

<table>
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<tr>
<th>Verbal</th>
<th>Video</th>
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<tbody>
<tr>
<td>22%</td>
<td>91%</td>
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Agency in charge is CMS

“formal SDM interaction”

evidence-based decision tool”
Medicaid will cover advance care planning

“Advance care planning shall consist . . . SDM . . . decision aids”

BUT

Link ACP reimbursement to PDA use?
Obstacle

PDAs widely varying quality

ACP PDA too

Cannot attach legal consequences

Assure PDA quality

Certification
2017

Contract with an entity to “synthesize evidence” and establish “consensus based standards”
End of life

CPR (6)
Advanced cancer
Advanced disease
Advanced heart failure
Advanced liver disease
Advanced lung disease
Closer look for people with a serious illness

Goals of care (5)
Advanced cancer
Advanced disease
Advanced heart failure
Advanced lung disease
Family meetings in the ICU

Hospice (3)
Advanced cancer
Skilled nursing facility
Introduction

Other
Dialysis for patients 75+
Long-term tube feeding
Help with breathing
Medical care for serious illness
Advanced lung cancer patient
Other vetted ACP PDAs

Medicare does not yet require PDA ACP yet

Look at the WA PDAs

Conclusion
Medical Futility Blog

Since 2007, I have been blogging, almost daily, to medicalfutility.blogspot.com. This blog focuses on reporting and discussing legislative, judicial, regulatory, medical, and other developments concerning end-of-life medical treatment conflicts. The blog has received over 3 million direct visits. Plus, it is redistributed through WestlawNext, Bioethics.net, and others.

Materials from the cases discussed in this presentation are available at http://thaddeuspope.com