Advance Care Planning and
The Conversation Project

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PCQN August 13, 2015
Objectives

- Understand current state of advance care planning in the United States
- Discuss impact of advance care planning on medical care delivery to patients
- Review developments in advance care planning, including The Conversation Project
Autonomy

- American society strongly values autonomy
- Past 50 years deference to patient autonomy has gradually replaced paternalism
- Prompted by legal cases where families contested life-sustaining care that physicians imposed upon patients
- Culminated in Patient Self Determination Act 1991, which protects right of patients to accept or refused treatments, make their own medical decisions


Advance Care Planning

- Advance care planning helps to honor patient autonomy around end of life care
- Honors patient preferences and goals if incapacitating illness or injury prevents adequate communication
- ACP designates patient choices about medical care for when a patient is unable to indicate their preference
- Choices depend upon patient’s care goals
  - Some prioritize longer life
  - Some choose not to prolong life if QOL unacceptable
- Affected by religious and spiritual values and beliefs
90% of people say that talking with their loved ones about end-of-life care is important.

Only 27% have actually done so.

60% of people say that making sure their family is not burdened by tough decisions is "extremely important."

But 56% have not communicated their end-of-life wishes.

Source: Centers for Disease Control (2005)
80% of people say that if seriously ill, they would want to talk to their doctor about end-of-life care.

Only 7% report having had an end-of-life conversation with their doctor.

Source: Survey of Californians by the California HealthCare Foundation (2012)
82% of people say it’s important to put their wishes in writing.

23% have actually done it.

Source: Survey of Californians by the California HealthCare Foundation (2012)
70% of people say they prefer to die at home.

76% die in an institution (hospital, nursing home or long-term-care facility), and receive more aggressive, invasive, poorer quality care than they would at home.

Drastic need for expansion and improvement of ACP in US

• 2003 Agency for Healthcare Research and Quality (AHRQ) report: fewer than 50% of severely or terminally ill patients had an advance directive in their medical records

• Advance directives helped make end-of-life decisions in less than half of the cases where advance directives existed


• The care that people receive at end of life does not often fulfill their wishes, and is often more aggressive and invasive than desired.

7 of 10 Americans die from chronic disease.

9 of 10 deaths in Medicare population are associated with these chronic illnesses:
- Congestive heart failure
- Chronic lung disease
- Cancer
- Coronary artery disease
- Renal failure
- Peripheral vascular disease
- Diabetes
- Chronic liver disease
- Dementia

Dartmouth Atlas of Health Care www.dartmouthatlas.org
Chronic Illness in America

- Health declines slowly
- Marked by sudden severe episodes of illness requiring hospitalization
- Pattern repeated over and over with overall health steadily declining
- Considerable uncertainty about when death is likely to occur
- Patients often not told condition is terminal
- No clear threshold between acutely ill and actually dying
- Patients often too ill to speak for themselves - physicians and family/surrogate make decisions
• 32% of total Medicare spending is for patients with chronic illness in their last two years of life (physician and hospital fees associated with repeated hospitalizations)

• Patients don’t get the kind of care they would want - they prefer a more conservative pattern of end of life care than they receive

• Patients with severe chronic illness who receive more intensive inpatient care do not have improved survival, better quality of life, or better access to care

• Patients’ experience of care differs dramatically; regions with much more aggressive medical patterns see medical specialists more frequently, spend more days in the hospital, die in an ICU more often

Robert Wood Johnson Foundation
International Comparison of Spending on Health, 1980–2009

Average spending on health per capita ($US PPP*)

Total expenditures on health as percent of GDP

* PPP=Purchasing Power Parity.

Source: Commonwealth Fund National Scorecard on U.S. Health System Performance, 2011.
Cost: Hospital Spending per Discharge, 2009
Adjusted for Cost of Living

<table>
<thead>
<tr>
<th>Country</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>US*</td>
<td>17,206</td>
</tr>
<tr>
<td>CAN*</td>
<td>12,163</td>
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<tr>
<td>NETH</td>
<td>11,988</td>
</tr>
<tr>
<td>SWITZ</td>
<td>9,398</td>
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<tr>
<td>NOR*</td>
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<tr>
<td>SWE</td>
<td>9,026</td>
</tr>
<tr>
<td>NZ</td>
<td>7,312</td>
</tr>
<tr>
<td>OECD Median</td>
<td>7,295</td>
</tr>
<tr>
<td>Median</td>
<td>7,312</td>
</tr>
<tr>
<td>AUS*</td>
<td>4,667</td>
</tr>
<tr>
<td>FR</td>
<td>4,527</td>
</tr>
</tbody>
</table>

Source: OECD Health Data 2009 (June 2009).
Organization for Economic Development and Cooperation

Among OECD member nations, the United States has the:

Lowest life expectancy at birth.
Highest mortality preventable by health care.
Medical Spending in the U.S.

$2.9 trillion in 2010

The costliest 5% account for 50% of all healthcare spending

CBO May 2009 High Cost Medicare Beneficiaries www.cbo.gov
nchc.org/facts/cost.shtml
Institute of Medicine Report on Dying In America

IOM report released September 2014

- Comprehensive report on current state of medical care for persons with serious illness or medical condition approaching death
- Consensus study assessed:
  - Delivery of medical care, social, and other supports to both patient and family
  - Patient-family-provider communication of values, preferences, and beliefs
  - Advance care planning
  - Health care costs, financing, and reimbursement
  - Education of health professionals, patients, families, employers, and the public at large
- Focused extensively on people with serious and chronic illness of indeterminate prognoses
- Why the current health care system has largely failed to meet their needs, including advance care planning
Findings, Clinician-Patient Communication:

- Most people nearing the end of life are not physically, mentally, or cognitively able to make their own decisions about care.
- Of people who indicate their EOL care preferences, most choose care focused on alleviating pain and suffering.
- Frequent clinician-patient conversations about EOL care values, goals, and preferences are necessary to avoid unwanted treatment.
- Incentives, quality standards, and system support are needed to promote improved communication skills and more frequent conversations.
Recommendation:

Professional societies and other organizations that establish quality standards should develop standards for clinician–patient communication and advance care planning that are measurable, actionable, and evidence based. These standards should change as needed to reflect the evolving population and health system needs and be consistent with emerging evidence, methods, and technologies.

Payers and health care delivery organizations should adopt these standards and their supporting processes, and integrate them into assessments, care plans, and the reporting of health care quality.
Providing ACP assistance to patients with advanced illnesses

- Positively impacts quality of life
- Improves patient and family satisfaction
- Reduces surviving family anxiety and depression


- Associated with reduction in healthcare costs in patients dying with advanced cancer

What impact does ACP have?

ACP increases overall satisfaction with the health care process.


Patients with advanced illnesses, including metastatic cancer, may receive more aggressive treatment than they want because they have not discussed their end-of-life care preferences with their doctor.


What impact does ACP have?

Patients who received advance care planning or palliative care interventions consistently showed a pattern toward decreased ICU admissions and reduced ICU length of stay, and likely health care cost savings.


A comprehensive ACP program with high completion of advance directive suggests reduced health care costs in last 2 years of life as compared to national average.


The Dartmouth Atlas of Health Care www.dartmouthatlas.org
What impact does ACP have?

Angelo Volandes, MD and team at Harvard developed videos to show patients and families visually what invasive medical care looks like ie. ICU, CPR, intubation and mechanical ventilation - “ACP Decisions”

150 hospitalized patients with prognosis 1 year or less randomized to verbal narrative vs. 3 min video describing CPR and intubation.

Patients who viewed videos were more than twice as likely to request DNR, DNI status at time of discussion and at discharge than control subjects.

What impact does ACP have?

“ACP Decisions” video outcomes:

150 patients at 4 cancer centers in Boston with advanced cancer randomized to verbal narrative vs. CPR video.

Participants with advanced cancer who viewed video of CPR were less likely to opt for CPR than those who listened to a verbal narrative (request for resuscitation decreased from 48% to only 20% with video)

ACP Decision Aids

Support 3 key components of the process:
• Learning about anticipated conditions and options for care
• Considering these options
• Communicating preferences for future care, either orally or in writing

Decision aid benefit depends on the patient's current health status and the predictability of illness trajectories:
• Healthy persons benefit most from general decision aids focused on choice of health care proxies, goals of care for hypothetical catastrophic situations
• For patients with serious illness, appropriate aids focus on decisions to accept, withhold, or terminate specific treatments
Decision aids improve advance care planning by facilitating clear documentation and by offering insights into why patients make the choices they do.

• Only 12% of patients with an advance directive had received input from their physician in its development.
• Physicians were accurate only about 65% of the time when predicting patient preferences.


Examples:

• **My Directives** – online platform for advance directives
  
  Mydirectives.com

• **Five Wishes** – document specifies care preferences, meets legal requirements as advance directive in most states
  
  Agingwithdignity.org/five-wishes.php

• **Consumer’s Toolkit for Health Care Advance Planning** – American Bar Association toolkit
  
  Americanbar.org

• **Caring Conversations** – Center for Practical Bioethics toolkit
  
  Practicalbioethics.org/resources/caring-conversations

• **The Conversation Project** – Starter Kit and How to talk to your doctor kit
  
  Theconversationproject.org
Move from hypothetical to actual clinical decisions as patient and family familiarity with health states increases. Should be staged approach:

- Healthy persons encouraged to choose and document medical POA, complete general AD
- Patients with advanced illness provided specific information on condition, options for life-sustaining treatments, encouraged to name medical POA
  - Disease-specific tools
Information needed for advance care planning for patients with advanced illness:

- Prognosis
  - More difficult for diseases with less certain prognosis ie. heart disease, dementia
- Implications of health care decisions
- Expected natural history of their condition
- Efficacy or lack thereof or harm of various life-sustaining interventions
- Ongoing process rather than one-time decision, revised as the patient's familiarity with their illness increases or disease progresses
Examples:

- Oregon Health Decisions Workbook
- PEACE (Patient Education and Caring: End-of-life) Series from American College of Physicians
- Healthwise:
  - Should I have Artificial Hydration and Nutrition?
  - Should I stop kidney dialysis?
  - Should I receive CPR and Life Support?
  - Should I stop Treatment that Prolongs my life?
OR was the first state to enact POLST

POLST = “Physician Orders for Life-Sustaining Treatment”

- Resuscitation (attempt or do not attempt resuscitation)
- Aggressiveness of medical interventions (full treatment, limited interventions, comfort measures only)
- Artificially administered nutrition (long term, defined trial, or no artificial nutrition by tube)

16 states (OR, CA, WA, ID, MT, HA, UT, CO, IA, LA, NY, PA, WV, NC, TN, GA) have endorsed POLST or variation laws

30 other states have programs under development
### Physician Orders for Life-Sustaining Treatment (POLST)

Follow these medical orders until orders change. Any section not completed implies full treatment for that section.

<table>
<thead>
<tr>
<th>A</th>
<th>CARDIOPULMONARY RESUSCITATION (CPR): Unresponsive, pulseless, &amp; not breathing.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Attempt Resuscitation/CPR&lt;br&gt;Do Not Attempt Resuscitation/DNR&lt;br&gt;If patient is not in cardiopulmonary arrest, follow orders in B and C.</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>B</th>
<th>MEDICAL INTERVENTIONS: If patient has pulse and is breathing.</th>
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<tbody>
<tr>
<td></td>
<td>Comfort Measures Only. Provide treatments to relieve pain and suffering through the use of any medication by any route, positioning, wound care and other measures. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. Patient prefers no transfer to hospital for life-sustaining treatments. Transfer if comfort needs cannot be met in current location. Treatment Plan: Provide treatments for comfort through symptom management.</td>
</tr>
<tr>
<td></td>
<td>Limited Treatment. In addition to care described in Comfort Measures Only, use medical treatment, antibiotics, IV fluids and cardiac monitor as indicated. No intubation, advanced airway interventions, or mechanical ventilation. May consider less invasive airway support (e.g. CPAP, BiPAP). Transfer to hospital if indicated. Generally avoid the intensive care unit. Treatment Plan: Provide basic medical treatments.</td>
</tr>
<tr>
<td></td>
<td>Full Treatment. In addition to care described in Comfort Measures Only and Limited Treatment, use intubation, advanced airway interventions, and mechanical ventilation as indicated. Transfer to hospital and/or intensive care unit if indicated. Treatment Plan: All treatments including breathing machine.</td>
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| Additional Orders: |

<table>
<thead>
<tr>
<th>C</th>
<th>ARTIFICIALLY ADMINISTERED NUTRITION: Offer food by mouth if feasible.</th>
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<tbody>
<tr>
<td></td>
<td>Long-term artificial nutrition by tube. Additional Orders (e.g., defining the length of a trial period):</td>
</tr>
<tr>
<td></td>
<td>Defined trial period of artificial nutrition by tube.</td>
</tr>
<tr>
<td></td>
<td>No artificial nutrition by tube.</td>
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<table>
<thead>
<tr>
<th>D</th>
<th>DOCUMENTATION OF DISCUSSION: (REQUIRED) See reverse side for add’l info.</th>
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<tbody>
<tr>
<td></td>
<td>Patient (If patient lacks capacity, must check a box below)</td>
</tr>
<tr>
<td></td>
<td>Health Care Representative (legally appointed by advance directive or court)</td>
</tr>
<tr>
<td></td>
<td>Surrogate defined by facility policy or Surrogate for patient with developmental disabilities or significant mental health condition (Note: Special requirements for completion- see reverse side)</td>
</tr>
<tr>
<td></td>
<td>Representative/Surrogate Name: Relationship:</td>
</tr>
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<table>
<thead>
<tr>
<th>E</th>
<th>PATIENT OR SURROGATE SIGNATURE AND OREGON POLST REGISTRY OPT OUT</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Signature: recommended&lt;br&gt;This form will be sent to the POLST Registry unless the patient wishes to opt out, if so check opt out box:</td>
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<table>
<thead>
<tr>
<th>F</th>
<th>ATTESTATION OF MD / DO / NP / PA (REQUIRED)</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>By signing below, I attest that these medical orders are, to the best of my knowledge, consistent with the patient's current medical condition and preferences.</td>
</tr>
<tr>
<td></td>
<td>Print Signing MD / DO / NP / PA Name: required&lt;br&gt;Signer Phone Number: Signer License Number: (optional)</td>
</tr>
<tr>
<td></td>
<td>MD / DO / NP / PA Signature: required&lt;br&gt;Date: required&lt;br&gt;Office Use Only</td>
</tr>
</tbody>
</table>

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED

SUBMIT COPY OF BOTH SIDES OF FORM TO REGISTRY IF PATIENT DID NOT OPT OUT IN SECTION E

© CENTER FOR ETHICS IN HEALTH CARE, Oregon Health & Science University
HIPAA PERMITS DISCLOSURE TO HEALTH CARE PROFESSIONALS & ELECTRONIC REGISTRY AS NECESSARY FOR TREATMENT

Information for patient named on this form

PATIENT’S NAME: __________________________

The POLST form is always voluntary and is usually for persons with serious illness or frailty. POLST records your wishes for medical treatment in your current state of health (states your treatment wishes if something happened tonight). Once initial medical treatment is begun and the risks and benefits of further therapy are clear, your treatment wishes may change. Your medical care and this form can be changed to reflect your new wishes at any time. No form, however, can address all the medical treatment decisions that may need to be made. An Advance Directive is recommended for all capable adults and allows you to document in detail your future health care instructions and/or name a Health Care Representative to speak for you if you are unable to speak for yourself. Consider reviewing your Advance Directive and giving a copy of it to your health care professional.

Contact Information (Optional)

Health Care Representative or Surrogate:

Relationship: __________________________

Phone Number: __________________________

Address: __________________________

Health Care Professional Information

Preparer Name: __________________________

Preparer Title: __________________________

Phone Number: __________________________

Date Prepared: __________________________

PA’s Supervising Physician: __________________________

Phone Number: __________________________

Primary Care Professional: __________________________

Directions for Health Care Professionals

Completing POLST

• Completing a POLST is always voluntary and cannot be mandated for a patient.
• An order of CPR in Section A is incompatible with an order for Comfort Measures Only in Section B (will not be accepted in Registry).
• For information on legally appointed health care representatives and their authority, refer to ORS 127.505 - 127.580.
• Should reflect current preferences of persons with serious illness or frailty. Also, encourage completion of an Advance Directive.
• Verbal/phone orders are acceptable with follow-up signature by MD/DO/NP/PA in accordance with facility/community policy.
• Use of original form is encouraged. Photocopies, faxes, and electronic registry forms are also legal and valid.
• A person with developmental disabilities or significant mental health condition requires additional consideration before completing the POLST form; refer to Guidance for Health Care Professionals at www.or.polst.org.

Oregon POLST Registry Information

Health Care Professionals:

(1) You are required to send a copy of both sides of this POLST form to the Oregon POLST Registry unless the patient opts out.

(2) The following sections must be completed:

• Patient’s full name
• Date of birth
• MD/DO/NP/PA signature
• Date signed

Updating POLST: A POLST Form only needs to be revised if patient treatment preferences have changed.

This POLST should be reviewed periodically, including when:

• The patient is transferred from one care setting or care level to another (including upon admission or at discharge), or
• There is a substantial change in the patient’s health status.

If patient wishes haven’t changed, the POLST Form does not need to be revised, updated, rewritten or resent to the Registry.

Voiding POLST: A copy of the voided POLST must be sent to the Registry unless patient has opted out.

• A person with capacity, or the valid surrogate of a person without capacity, can void the form and request alternative treatment.
• Draw line through sections A through E and write “VOID” in large letters if POLST is replaced or becomes invalid.
• Send a copy of the voided form to the POlst Registry (required unless patient has opted out).
• If included in an electronic medical record, follow voiding procedures of facility/community.

For permission to use the copyrighted form contact the OHSU Center for Ethics in Health Care at orgpolst@ohsu.edu or (503) 418-3066. Information on the Oregon POLST Program is available online at www.or.polst.org or at orgpolst@ohsu.edu

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED, SUBMIT COPY TO REGISTRY

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## POLST vs. Advance Directive

### POLST
- Indicates patient wishes for aggressiveness of care at present time
- Intended for patients with serious illness or medical frailty
- Medical orders signed by provider

### Advance Directive
- Indicates wishes for aggressiveness of care in potential future situations (close to death, permanently unconscious, advanced progressive illness, extraordinary suffering)
- Intended for everyone
- Legally recognized document (cannot be interpreted or honored by emergency providers)
Respecting Choices – Gunderson Lutheran

- LaCrosse, Wisconsin with high penetration of one healthcare system and insurance structure
- Medical ethicist Dr. Bud Hammes initiated a formal ACP program
- Process of communication about healthcare options
- Standardized throughout the healthcare system
- Marked infrastructure = trained personnel to facilitate and assist patients and families with these discussions
- Individualized assistance based on a patient’s state of health to help them
  - Understand their future healthcare options
  - Reflect on personal values, goals, religious, or cultural beliefs
  - Talk to physicians, healthcare agents, other loved ones as needed
Respecting Choices ACP Model

Three tier ACP based on patient state of health

- First Steps ACP
- Next Steps ACP
- Last Steps ACP
First Steps ACP

• **Routine healthcare for all patients over the age of 55-65**

• **Wishes for life-sustaining treatment if the person suffers a severe, neurologic injury or illness and unlikely to recover**

• **Initiated at routine annual physical examinations by PCPs**
Next Steps ACP

- Patients with chronic, progressive illness, functional decline, medical comorbidities, recurrent hospitalizations
- Risk for illness that might leave them unable to express their own wishes about their healthcare decisions
- Understand trajectory of illness, possible complications, life-sustaining treatments that may be offered if illness progresses
- Patient’s health care decision maker and family are involved
- Component of chronic disease management
Last Steps ACP

- **Prognosis of 12 months or less**
- Patients who live in long-term care facilities, at high risk for complications, at risk of losing their decision-making capacity
- CPR, artificial life-support, artificially administered nutrition and hydration, comfort care options discussed
- POLST completed to document wishes
Respecting Choices – Gunderson Lutheran

- Instituted in the early 1990’s in LaCrosse, Wisconsin
- 540 Gunderson Healthcare system decedents study
- Very high prevalence of advance directives (85%)
- 95% of advance directives documented in the medical record
- Almost all advance directives requested to forgo aggressive life-sustaining treatments as death neared
- 98% of the patient deaths involved forgoing aggressive treatments and transition to comfort measures

The Conversation Project

• Co-founded by Pulitzer Prize-winner Ellen Goodman and developed in collaboration with Institute for Healthcare Improvement

• Public engagement campaign with the transformative goal to have every person’s end-of-life wishes expressed and respected

• Dedicated to helping people talk about their wishes for end-of-life care

• The Conversation should be had at the kitchen table, not in ICU
The Conversation Ready Project - Pioneer Sponsors

- Institute for Healthcare Improvement sponsored initiative
- Prepare health care delivery systems to receive and respect patients’ wishes about end-of-life care
- 14 original Pioneer Sponsors committed to ensuring their health systems are “Conversation Ready” by developing and piloting processes, expanded to dozens of interested health care systems through IHI
The Conversation Ready Project - Pioneer Sponsors

• Reframe the provider-patient relationship around the question, “What matters most to you?”

• Ultimate objective is to package proven methods and strategies to other health care systems nationally
  • Reach out to patients about their end-of-life wishes
  • Record end-of-life wishes in accessible fashion (EMR)
  • Respect patient wishes for end-of-life care
Conclusions

• The current state of advance care planning in the United States is dismal. This is being recognized, and great efforts are being made nationally to improve it.

• Encouraging advance care planning honors patient and family autonomy which is highly valued in American society.

• Advance care planning has the opportunity to help patients avoid potentially non-beneficial invasive treatments and procedures that they do not want to receive (that are costly), and therefore positively impact the financial outlook of the American health care system.
How To Talk To Your Doctor
(or any member of your health care team)

Your Conversation Starter Kit

Creating America’s healthiest community, together.