Advance Care Planning: Where Does MOLST Fit?

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Co-Director, Community-wide End-of-life/Palliative Care Initiative
Objectives

- Define the Advance Care Planning process and recognize the need for advance care planning along the health-illness continuum
- Review the development of the MOLST form and identify when to use the MOLST Program
- Discuss MOLST as a POLST Paradigm Program that converts the patient treatment goals into medical orders and ensures that information is transferable and applicable across care settings (LTC, EMS and hospital)
Story with a Positive Outcome

• Advance Care Planning occurs
• Appropriate preparation for discussion
• Antecedent conversation occurs with physician and within family
• Goals guide care
• Documents exist, are regularly updated and are available
Difficult Clinical Stories

- Agent/Family disagree with physician assessment
- Agent/Physician agree while another family disagrees and interferes
- Agent/Family desire focus on QOL and physician disagrees
- Disagreement among physicians
- No agent/family; patient lacks capacity
Life is a story

Beginning
Middle
End
Who writes our final chapter?

Will we die in a manner consistent with the way we lived, which respects our personal values, spiritual beliefs, cultural background, & preserves our dignity?
Who makes the decisions?

- Health Care “Agent”
- Family/friends
- Strangers
- The Government
Advance Care Planning: What Is It?

- Process of planning for future medical care if you are unable to make your own decisions
- Applies **ONLY** when you are unable to speak for yourself
- Important for **ALL** adults (age 18+) to do
- A “Gift” to ourselves and our loved ones
Advance Care Planning

Compassion, Support and Education along the Continuum

- Advancing chronic illness
- Chronic disease or functional decline
- Healthy and independent
- Multiple co-morbidities, with increasing frailty
- Death with dignity
- Maintain & maximize health and independence

Maintain & maximize health and independence
Advance Care Planning

• Appropriate for all adults and for the subset with life-limiting illness
• Process of planning for future medical care if you lose decisional capacity
• Focuses on conversation and addresses surrogate decision-making and end-of-life preferences
• Process results in the completion and use of legal documents
Advance Care Planning

- Reflect ongoing conversation with periodic reassessment and as needed
- Legal documents must be accessible
- Legal documents are helpful in preventing situations illustrated by Karen Ann Quinlan, Nancy Cruzan and Terri Schiavo
- Decreases turmoil and suffering and eases the burden for families of persons with life-limiting illness
Advance Care Directives

- **1991 - Patient Self-Determination Act**
  - 20% had a form of Advance Care Directive
  - 75% approved of a Living Will

- **2002 - Means to a Better End**
  - 15 -20% Americans have ACD
  - 20% of LTC patients have ACD
Advance Care Planning: A Gift

- Clarify values, beliefs
- Choose a spokesperson
- Understand life-sustaining treatments
- Practical issues

Compassion and Support at the End of Life
Advance Care Directives

For All Adults

- Health Care Proxy Form
- Living Will
- Organ Donation (optional)

For Those Who Are Chronically Ill or Near the End of Their Lives

- Nonhospital Do Not Resuscitate (DNR) Order
- Medical Orders for Life Sustaining Treatment (MOLST) form
How to Clarify Values and Beliefs

• Your values
• Your personal beliefs
• Your spiritual beliefs
• What makes life worth living
• What really matters to you
• Your hopes and wishes
• Your goals for care

Speak to your

• Spokesperson (Agent)
• Family
• Spiritual Adviser
• Physician
How to Choose a Spokesperson

• Knows me well
• Understands what is important to me
• Will talk about sensitive wishes now
• Will listen to my wishes
• Willing to speak on my behalf
• Would act on my wishes
• Can separate his/her feelings from mine
How to Choose a Spokesperson

- Will be available in the future
- Lives close by or willing to come
- Could handle responsibility
- Can manage conflict resolution
- Meets legal criteria
Life-Sustaining Treatments

• Benefits and burdens
• Treatment can be refused or accepted
• Cannot always predict recovery
• Life support may be short-term
• Time-limited trials
• Treatments can be discontinued
JUST SO YOU KNOW...

I NEVER WANT TO LIVE IN A VEGETATIVE STATE, DEPENDENT ON SOME MACHINE.

IF THAT EVER HAPPENS, JUST UNPLUG ME, OK?

OK.

Hey!
Shared Medical Decision Making

• Will treatment make a difference?
• Do burdens of treatment outweigh benefits?
• Is there hope of recovery?
  – If so, what will life be like afterward?
• What does the patient value?
  – What is the goal of care?
Practical Issues: Accessibility

• Keep a copy
• Provide a copy
  – Spokesperson (Agent)
  – Alternate Spokesperson
  – family members / loved ones
  – primary care physician
  – all health care providers
  – primary hospital
  – spiritual adviser
Practical Issues: Review and Update

- Periodically
- Major life events
- Newly diagnosed chronic illness
- Advancing chronic illness
- After complicated life-sustaining treatments
“Doctor, I’ve thought it over, and I’d rather not undergo any heroic efforts.”
Advance Care Planning

Compassion, Support and Education along the Continuum

Advancing chronic illness

Chronic disease or functional decline

Healthy and independent

Maintain & maximize health and independence

Multiple co-morbidities, with increasing frailty

Death with dignity
**POLST in Oregon**

- **Physician Orders for Life-Sustaining Treatment (POLST)**
- **Bright pink medical order form for seriously ill patients**
- **Signed by MD, DO or NP**
- **Turns patient preferences into orders**
- **Goal**: ensure wishes are honored
POLST Research

• Study of 180 nursing home residents
  – comfort measures only
  – do not resuscitate (DNR) order
  – transfer to hospital only if comfort measures fail

POLST Research

• **Findings**
  - no one received CPR, ICU care or vent
  - 63% had orders for narcotics
  - 2% hospitalized to extend their lives
  - 13% overall hospitalized

• **Summary**
  - POLST CPR orders respected
  - high comfort care
  - low rates of transfer for aggressive life-prolonging treatments
POLST : Research

• Study of 58 older adults enrolled in a Program for All-Inclusive Care for the Elderly (PACE)

• Reviewed POLST form and records from last two weeks of life

Lee, Brummel-Smith, Meyer, Drew and London (JAGS 2000)
POLST: Research

• Findings
  – CPR use: consistent with directions for 91% of participants
  – Medication use: consistent for 46% of participants
    • 33% less invasive, 20% more invasive
  – Antibiotics given: consistent for 86% who had infections
  – Feeding tube use: consistent for 94%, IV fluids for 84%
POLST: Research

• Summary
  – effective in ensuring treatment wishes are honored about CPR, antibiotics, IV fluids and feeding tubes
  – less effective for medical interventions
  – more consistently followed than previously reported for advance directive forms

Lee, Brummel-Smith, Meyer, Drew and London (JAGS 2000)
POLST Outcomes: Completed AD

- **1993**: 70% of Portland NH residents had DNR orders (Teno, et al)

- **1996**: 91% with written DNR orders in 8 Oregon NH’s (Tolle, et al)

- **1997**: 475 randomly selected Oregon decedents:
  - 67% with written AD
  - 93% family felt they knew wishes
POLST Outcomes: Site of Death

Oregon residents who die in hospital

- 1980: 50%
- 1993: 35% (national average: 56%)
- 1999: 31% (lowest rate in the US)
## Site of Death: National and State Data

<table>
<thead>
<tr>
<th></th>
<th>Deaths at home</th>
<th>Deaths in a Hospital</th>
<th>Deaths in a NH</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oregon (Nat'l Benchmark)</td>
<td>35.10%</td>
<td>32.50%</td>
<td>32.40%</td>
</tr>
<tr>
<td>National Mean (Average)</td>
<td>24.90%</td>
<td>50.00%</td>
<td>25.10%</td>
</tr>
<tr>
<td>New York</td>
<td>21.20%</td>
<td>61.80%</td>
<td>17.00%</td>
</tr>
</tbody>
</table>
MOLST

- Medical Orders for Life-Sustaining Treatment
- Created by the Community-wide End-of-Life/Palliative Care Initiative in 2003
- Adapted from Oregon’s POLST
- Combines DNR, DNI, and other Life-Sustaining Treatments
- Incorporates NYS law

November 2003

www.compassionandsupport.org
Pink MOLST Form

- **Consistent color**: easily identifiable
  - facilitate appropriate care desired by patient
- **Accuracy**: clear, unambiguous medical orders
- **Flexible**: changes can be made sequentially
  - Does not need to be done with each admission
- **Portable**: transfer PINK across systems
- **Availability**: Original PINK MOLST with the patient; make copy to retain in the chart
Health Care Proxy/Living Will and MOLST

Health Care Proxy/Living Will
- completed ahead of time
- applies only when decision-making capacity is lost

MOLST
- applies right now
- not conditional on losing decision-making capacity
- set of physician orders
- may carry more weight in medical settings
Revised MOLST Form

Page 1: **DNR**
- Complete Section A, B, C for DNR
- Section D: Advance Directives

Page 2: **Life-Sustaining Treatment**

Page 3 and 4: **Renew/Review Section**

Supplemental Documentation Forms for
- DNR: Adult and Minor

*Revised October 2005, Approved for use by NYSDOH*
MOLST Form Section A

Section A Resuscitation Instructions
– Patient has no pulse and is not breathing

Orders
– Do Not Resuscitate (DNR) *
  • no CPR, intubation, mechanical ventilation
– Full Cardio-Pulmonary Resuscitation (CPR)
  • No Limitations

*Supplementary forms for those who lack decisional capacity

Revised October 2005, Approved for use by NYSDOH
MOLST Form Section B - D

B Patient/Resident/Health Care Agent/or Surrogate Decision-Maker Consent for Section A: DNR
  - DNR(CPR) Patient/Resident Consent With Decision-Making Capacity
  - DNR(CPR) Patient/Resident Consent Without Decision-Making Capacity*

C Physician Signature for Section A and B

D Advance Directives

*Supplementary forms for those who lack decisional capacity

Revised October 2005, Approved for use by NYSDOH
Supplemental Documentation
Forms for MOLST-DNR*

Form for Adults
- Section 1:
  • Lack decisional capacity
- Section 2:
  • Therapeutic exception
  • Medical futility and no surrogate
  • Residents of OMH and OMRDD Facilities
  • Residents of Correctional Facilities

Form for Minors
- Under age 18 and not married or a parent

*Required by NYS regulation for DNR

Revised October 2005, Approved for use by NYSDOH
MOLST Form Part E

Orders for Other Life-Sustaining Treatment and Future Hospitalization

(patient/resident has pulse and/or is breathing)

- Additional Treatment Guidelines
- Intubation and Mechanical Ventilation
- Future Hospitalization/Transfer
- Artificially Administered Fluids and Nutrition
- Antibiotics and Other Instructions
- Consent

Revised October 2005, Approved for use by NYSDOH
Additional Treatment Guidelines

- Comfort measures only
  - treat with dignity and respect
  - offer food and fluids by mouth
  - medication, positioning, wound care
  - relieve pain and suffering
  - oxygen, suctioning
- Limited medical interventions
  - oral/IV antibiotics, cardiac monitoring
- No limitations on medical interventions

Revised October 2005, Approved for use by NYSDOH
MOLST Form Consent for Part E

- Physician may complete form for patient with capacity or with Health Care Agent with Section E consent.
- Physician may complete form for incapacitated patients without Health Care Agent only with clear and convincing evidence and with Section E consent.
- Physician should consult legal counsel for MR/DD patients without capacity. See Surrogate’s Court Procedure Act §1750-B.

Revised October 2005, Approved for use by NYSDOH
MOLST Form Part E

- If patient has decision-making capacity, patient should be consulted prior to treatment or withholding thereof.
MOLST Form Part E

• **Artificially Administered Fluids and Nutrition**
  - If Health Care Agent makes decision, it must be based on knowledge of patient/resident’s wishes.
  - If there is no Health Care Agent and the patient lacks capacity, decision must be based on clear and convincing evidence of the patient/resident wishes.

*Revised October 2005, Approved for use by NYSDOH*
Nonhospital Order Not to Resuscitate (DNR Order)

- Person's Name: ____________________________
- Date of Birth: ______/_____/_____
- Do not resuscitate the person named above.

- Physician's Signature: ______________________
- Print Name: ______________________________
- License Number: __________________________
- Date: ______/_____/_____

It is the responsibility of the physician to determine, at least every 90 days, whether this order continues to be appropriate, and to indicate this by a note in the person's medical chart.

The issuance of a new form is NOT required, and under the law this order should be considered valid unless it is known that it has been revoked. This order remains valid and must be followed, even if it has not been reviewed within the 90 day period.

MOLST Does NOT Replace the NYS Nonhospital Order Not to Resuscitate form (DNR Order), except in Monroe and Onondaga Counties.
MOLST

Pre-Hospital & Acute Care

LTC

Office
MOLST: Who Should Have One?

• Anyone choosing:
  – Allow, embrace natural death
  – Do not resuscitate

• Anyone choosing to limit medical interventions

• Anyone eligible/residing in LTC facility

• Anyone who might die within the next year
MOLST Form Location

• In the home
  – Front of refrigerator
  – Back of bedroom door
  – Bedside table
  – On medicine cabinet

• Health care setting
  – Kept with patient between care settings
  – Hospital and LTC facility
    • Medical Chart
“There’s no easy way I can tell you this, so I’m sending you to someone who can.”
8-Step Protocol

1. Prepare for discussion
   – Understand the patient and family
   – Understand the patient’s condition and prognosis
   – Retrieve completed Advance Care Directives
   – Determine “Agent” (Spokesperson) or responsible party

2. Determine what the patient and family know
   – re: condition, prognosis

3. Explore goals, hopes and expectations

*Developed for NYS MOLST, Bomba, 2005*
8-Step Protocol

4. Suggest realistic goals
5. Respond empathetically
6. Use MOLST to guide choices and have patient/family share wishes
   – Shared medical decision making
   – Conflict resolution
7. Complete and sign MOLST
8. Review and revise periodically

Developed for NYS MOLST, Bomba, 2005
Advance Care Planning Community Goals

- Document the designated agent (surrogate decision maker) in a Health Care Proxy for every patient in primary, acute and long-term care and in palliative and hospice care.

- Document the patient/surrogate preferences for goals of care, treatment options, and setting of care at first assessment and at frequent intervals as condition changes.
Advance Care Planning Community Goals

- Convert the patient treatment goals into medical orders and ensure that the information is transferable and applicable across care settings, including long-term care, emergency medical services, and hospital, i.e., the Medical Orders for Life-Sustaining Treatments—MOLST, a POLST Paradigm Program.
Advance Care Planning Community Goals

- Make advance directives and surrogacy designations available across care settings

- Develop and promote healthcare and community collaborations to promote advance care planning and completion of advance directives for all individuals
Advance Care Planning Campaign
Rochester 2002
Community Conversations on Compassionate Care

- Increase comfort level in discussing death and dying
- Increase conversations that lead to completion of an Advance Care Directive

A Community-wide End-of-life/Palliative Care Initiative project

www.compassionandsupport.org
Stages of Readiness to Complete

- See no need
- Recognize need, but have barriers
- Ready to complete
- Advance Care Directive reflects wishes
- Advance Care Directive needs update
Readiness to Change

- **Precontemplation**: See no need
- **Contemplation**: Recognize need, but have barriers
- **Preparation**: Ready to complete
- **Action**: Advance Care Directive reflects wishes
- **Maintenance**: Advance Care Directive needs update
<table>
<thead>
<tr>
<th></th>
<th>Have Advance Directives</th>
<th>Do Not Have Advance Directives</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internal Employees</td>
<td>23%</td>
<td>77%</td>
</tr>
<tr>
<td>UPitt* and STEP EMS** Attendees</td>
<td>38%</td>
<td>62%</td>
</tr>
<tr>
<td>EPEC Attendees</td>
<td>49%</td>
<td>51%</td>
</tr>
<tr>
<td><strong>Facilitator Training Workshop Attendees</strong></td>
<td>60%</td>
<td>40%</td>
</tr>
<tr>
<td>All Attendees Including Community Members</td>
<td>44%</td>
<td>56%</td>
</tr>
</tbody>
</table>

Data was collected immediately prior to the workshop using the Health Care Proxy Readiness form.

* Geriatrics Conference for Health Care Professionals, University of Pittsburgh
** Emergency Medical Services conference, Rochester, NY
Community Conversations on Compassionate Care

Workshop Attendee Response

<table>
<thead>
<tr>
<th></th>
<th>Pre-Workshop</th>
<th>8-12 Weeks After Workshop</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have Advance Directives</td>
<td>44%</td>
<td>53%</td>
</tr>
<tr>
<td>Do Not Have Advance Directives</td>
<td>56%</td>
<td>47%</td>
</tr>
</tbody>
</table>

Improvement in people with advance directives from 44% to 53% is statistically significant (\( p < .01 \)).
CCCC CCCC Facilitator Training Agenda Facilitator Training Agenda

• 8-hour training
  – Advance Care Planning Along the Health-Illness Continuum
  – The Patient Voice in End-of-life Transitions
  – Life-Sustaining Treatments
  – Medical Orders for Life-Sustaining Treatments (MOLST)… a POLST paradigm
  – CCCC workshop logistics
  – Facilitation training
CCC Facilitator Training

- Trainees receive
  - comprehensive binder of information
  - workshop “tools”
  - facilitator resources
  - CD-ROM, featuring the binder information in PDF format and CCC Facilitator PowerPoint presentation with facilitator speaking notes
CCCC Facilitator Training

• Excellus BlueCross BlueShield support
  – partnership with trainees to offer the CCCC workshop in the community and to facilitate 1 on 1 discussions
  – supplies workshop folders and booklets
  – collects post-workshop data
  – analyzes pre-and post-workshop data for partners
Community Conversations on Compassionate Care

- # 110 CCCC workshops
- # 2637 participants
- # 186 trained facilitators

As of August, 2005
# Community Conversations on Compassionate Care Workshops

- Trained Facilitators
Questions?

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“Knowing is not enough; we must apply.
Willing is not enough; we must do.”

Goethe