At the Intersection:
Advance Care Planning and Medical Order Sets for the Seriously Ill in Missouri Long Term Care Settings

2018 Annual Meeting & Exposition
The Chase Park Plaza Royal Sonesta • St. Louis, Missouri
Breakout Session #32 • September 19, 2018

JOHN G. CARNEY, MEd - CENTER FOR PRACTICAL BIOETHICS
PATRICK WHITE, MD - BJC CHIEF MEDICAL OFFICER
SUSAN FRY, RN, MEd, TPOPP - LONG TERM CARE LIAISON
MATTHEW PJECHA, MSPP - CPB PROGRAM ASSOC. (TPOPP)
SHELLY WILLIAMSON (RESPONDENT) ADMINISTRATOR, DHSS SECTION LTC REGULATION

LeadingAge Missouri
Today’s Objectives

1. Distinguishing ACP from Medical Orders for the seriously ill community based long term care settings.

2. Describe Similarities and Distinctions between two kinds of Medical Orders (Transportable Physician Orders for Patient Preferences) and Missouri’s Out of Hospital Do Not Resuscitate Order (Purple Form)

3. Differentiate how standard of care approach to medical decision making assists in responding to patient preferences when PC goals are integrated into care planning for those living with serious life limiting illness.
Declarations and Conflicts of Interest

• Center for Practical Bioethics is official sponsor of Kansas-Missouri Transportable Physician Order for Patient Preferences (TPOPP), a National POLST Paradigm initiative. TPOPP relies on charitable support, grants, and nominal fees.
• CPB provides free and fee based training and resources on advance care planning for providers, patient and families.
• Presenters receive no personal benefit from the promotion of the program(s) or collateral materials presented in this training.
• Any US Patent Office registered marks or resources provided in accordance and within the limitations or patents issued.
• Resource Attributions and Citations provided as requested or required for use.
Creative Commons Attribution

• Ariadne Labs: Joint Center for Health Systems Innovation (www.ariadnelabs.org) and Dana-Farber Cancer Institute.

• Licensed under the Creative Commons Attribution-NonCommercial-ShareAlike 4.0 International License
  ◦ http://creativecommons.org/licenses/by-nc-sa/4.0/
Acknowledgements

Slides with symbols drawn from Serious Illness Care Program

Rachelle Bernacki, MD, MS,
Associate Director

Susan Block, MD
Director, Serious Illness Care Program
Advance Directives: Not Enough

• Focus on potentially life-prolonging treatments in limited set of circumstances
• Does not translate into medical orders for present circumstance
• Completion rate low
• Reliance on surrogate decision maker
• Not available
Traditional ACP

• For every adult – Healthy or not
• Future Oriented
• Goal is educational and reflective - Ponder values and share preferences
• Provide resources for them to think through and discuss with their family
• Potential outcomes:
  • Exploring values with family and loved ones. (Conversation only)
  • Provide guidance and direction
• Two Ends – Appointment of Agent and Direct Treatment

This is something all of us should do – NO clinical involvement required.
Advance Care Planning Terminology

Advance Care Planning = Planning in Advance of Serious Illness
Serious Illness Care Conversation = Planning in the context of progression of serious illness
Goals of Care Discussion = Decision making in context of clinical progression / crisis / poor prognosis
When is time to start Serious Illness Care Planning?

Asking the “surprise question” can help

- Would it surprise me if this person were to die in the next year? (answer of “no” means it’s time)
- NOTE: NOT the same as saying someone has a prognosis of a year or less
- NOTE: for cancer and renal patients, surprise question does a better job of predicting mortality than our current Medicare Hospice Certification criteria

Recognizing functional trajectories can help
Functional Trajectories

Illness Trajectory - #1
Sudden death - unexpected cause
(E.g., heart attack, traumatic event, etc.)

Illness Trajectory - #2
Steady decline - short terminal phase
(E.g., advanced cancer diagnosis)

Illness Trajectory - #3
Slow decline - periodic crisis - death
(E.g., progressive heart and lung disease)

Illness Trajectory - #4
Lingering, Expected Death
(E.g., advanced multiple chronic diseases)

Identifying the Seriously Ill population

FIGURE 9: Three Key Variables to Identify the Population in Need

**DIAGNOSIS**
- Cancer
- Advanced liver disease
- COPD with oxygen
- Heart failure
- Renal failure
- Advanced dementia
- Diabetes with complications
- ALS

**FUNCTIONAL IMPAIRMENT**
- Limitations in activities of daily living
  - eating
  - bathing
  - dressing
  - toileting
  - transferring
  - walking
- Significant memory loss
- DME—walkers, beds, home oxygen, etc.

**HIGH UTILIZATION**
- Hospital admissions, re-admissions, and length of stay
- Emergency Department visits
- Poly-pharmacy
- Skilled nursing/rehab stays
- Multiple home care episodes
## Advance Directive vs. POLST

<table>
<thead>
<tr>
<th>Advance Directive/ health care proxy</th>
<th>POLST</th>
</tr>
</thead>
<tbody>
<tr>
<td>For all adults</td>
<td>For those with chronic progressive illness or may die within the year</td>
</tr>
<tr>
<td>Complete for the future</td>
<td>Applies to person’s current situation. Medical orders for now.</td>
</tr>
<tr>
<td>In effect when decision-making capacity is lost</td>
<td>Not conditional on decision-making capacity</td>
</tr>
<tr>
<td>Contains no medical orders</td>
<td>Set of medical orders</td>
</tr>
<tr>
<td>May not be available in all settings</td>
<td>Accompanies patient across settings</td>
</tr>
</tbody>
</table>
So - What is POLST?

Physicians Orders for Life Sustaining Treatment (www.polst.org), started in Oregon in 1991

Converts patient preferences for treatment into:
- Orders move with patient across continuum
- Reviewed and respected as appropriate by providers along continuum – Relied on as best information available

>40 states presently working on paradigm development

Different names in different places (MOLST, POST, TPOPP), all have the same POLST paradigm elements
Term “POLST paradigm” used to describe programs with consistent components, but different names

- MOLST – New York (*Medical Orders)
- MOST – North Carolina (*Scope of Treatment)
- POST – West Virginia
- TPOPP – Kansas - Missouri (*Transportable PO Patient Preferences)

www.polst.org
POLST programs nationwide

Accessed on 09.10.18 at http://polst.org/programs-in-your-state/
POLST as Preferred Practice

“Compared with other advance directive programs, POLST more accurately conveys end-of-life preferences and yields higher adherence by medical professionals.”

National Quality Forum

Bringing POLST to Kansas and Missouri

• Named our project: Transportable Physician Orders for Patient Preferences (TPOPP)
• Started with KC Metro TPOPP taskforce 2009
• Pilot Topeka 2010-2011, still on ground there today
• Bi-State Coalition formed 2012
Community Coalition Approach

- Clinical consensus regarding standard of care
- Non-legislative route has greater flexibility and sustainability
- Keep pace better with changes in health care practice
- Still needs support from key regulatory entities and bodies like EMS, Departments of Health, Aging and Senior Services
- Organic process may take longer to implement statewide prolonging adoption
Community Coalition Model

Community Coalitions work locally to implement based on a standard of care and clinical consensus approaches

- 14 active local coalitions
- 12 additional interested communities
Elements of TPOPP Program – Process and Product

• PROCESS and FORM are distinct and discrete

• Process relies on engagement with patient and representative to understand values and preferences of the patient.

• Brings “future state” of traditional ACP into “real time” goal setting

• Clinician needs to ensure patient and family explore and understand patient’s compromised and vulnerable health status
TPOPP Process – 1st Determine Patient’s Wishes

• Assess patient to determine possible interventions.

• Assess situation to determine what treatment or interventions are indicated...AND

• Communicate with patient and/or the patient’s surrogate(s) to determine patient’s wishes

• Check hospital or system records for applicable orders (If patient’s primary physician is on same medical record system, POLST/TPOPP should be in record if primary care physician’s records are at hospital where patient presents)
Ask about Documentation of Patient’s Preferences

POLST/TPOPP
Advance Directive
DNR
Living Will
Remember Target populations, clarifying questions for patient and practitioners

TPOPP is for those who:

• Live with advanced progressive chronic illness.
• Are terminally ill.
• Who fits clinical profile of “Surprise Question”
  ▪ *Would you be surprised if the patient were to die in the next 12 months? NO is the answer for target population*
  ▪ Must be asked this way – Not the same as “Might the patient be alive this time next year?”
• Wish to further define their care wishes.
But it’s not for everybody

- TPOPP is not appropriate for person with stable medical condition or disabling problem with years of life expectancy.
- TPOPP is voluntary decision
Now it’s OK to move to the *form*

- A medical order (not an advance directive)
- Reflects patient’s current condition – not future
- Standardized look – bright pink
- Transfers with patient/resident
- Identifies positive and negative resuscitation status
- Also guides emergency personnel on what to do short of full arrest
- Reflects desire for or limitations to types of treatment interventions
- Includes other interventions, clarifying Goals, and Additional orders
Orders Based on ACP conversations

• Timely discussions
• Facilitated by trained professionals
• Helps establish medical goals of care
• Provides information on treatment options
• Builds decision making consensus among patient, family and medical team.
Using the TPOPP form
Using the TPOPP form

Section A: Resuscitation Status
- Attempt Resuscitation
- Do Not Attempt Resuscitation

Section B: Medical Interventions
- Full Treatment
- Limited Additional Interventions
- Comfort Measures Only

Section C: Medically Administered Nutrition
Using the TPOPP form

Section D: Signatures
- Patient or recognized decision maker
- Authorized healthcare provider and Physician

Section E: Guides for Additional Preferences
Completed TPOPP form

• Bright pink for quick identification.
• Kept in front of the medical chart.
• Form travels with patient to other settings (Copies OK)
• Can be entered into electronic medical record.
• Available in conspicuous location in home setting (e.g., fridge, bedside)
• EMS should be trained to look for, ask for form
• Should be reviewed upon any change in status or location of care
Standard of Care and Legislation

TPOPP AND “THE PURPLE FORM”
Is Legislation Needed?

• National POLST Paradigm Task Force does not have a preferred approach
• Legislation may or may not be needed
• National POLST Paradigm Task Force: POLST Legislative Guide helpful
• Legislative Risks: relate to agendas of supporters/opponents
• If legislation, best NOT including statutory form, too difficult to change and keep pace
Legislation may be needed, if/when...

• To remove specific impediments in current law
• Political realities may push in this direction
• Legislation may or may not help with statewide adoption and uniformity
• Health care practitioners may feel more reassured with legislation, including statutory immunity.
What about immunity?

Some stakeholders, legislators and provides prefer to build statutory immunity into law or regulations.

Statutory Immunity may not be possible in all political climates.

The Standard of Care is a solid legal standard on which to base end of life care.
MO’s Outside the Hospital Do Not Resuscitate...
The “Purple Form” and TPOPP

What is the Outside the Hospital Do Not Resuscitate Act?

When patients have made clear that they do not wish to be resuscitated in the event of cardiac or respiratory arrest, emergency medical services personnel are required to follow certain procedures. When treating patients outside a hospital, those procedures are outlined in the 2007 Missouri statute known as the “Outside the Hospital Do-Not-Resuscitate Act.” This law also provides liability protection for physicians, EMS personnel and health care facilities that honor an OHDNR order. Regulations regarding this law took effect August 30, 2009.

What is the purple form that is described in the OHDNR Act?

Currently, several forms are in use to express a patient’s desire not to be resuscitated. The purple form described in the new law is the preferred form. It clearly directs EMS personnel not to resuscitate the patient. The law states that this form may be signed only by the resident or a legally recognized “patient representative” such as an appointed agent or guardian. The preferred purple form is the only form that provides immunity from liability. However, that does not make other do-not-resuscitate forms invalid.

Does there need to be a purple form for each resident in the long-term care facility?

No, there is no regulatory requirement for long-term care or hospice facilities to have a signed purple form for every resident. In some cases, it may not be appropriate. In other cases, it may be impossible. Because some incapacitated residents do not have a legally recognized “patient representative,” the purple form cannot be properly executed.

What do I do if the resident is incapacitated and does not have a “patient representative”?

A physician can complete a DNR order for a resident if the physician determines the order is medically appropriate and in the resident’s best interest. If the resident has family, the physician should consult with them. Together, they can determine the resident’s best interest. Physician orders written by an attending physician or co-signed by a facility’s medical director may be an appropriate substitute for the purple form. If facilities maintain a policy that family members must concur with those orders, then documentation should be placed in the resident’s medical record. Documents prepared prior to a resident’s incapacitation are also acceptable.

Can nursing facility staff honor a signed physician DNR order if a resident suffers a cardiac arrest in a facility, even if the order does not meet the definition of being “properly executed” according to the regulation?

Any physician-signed DNR order is acceptable for regulatory compliance and should be honored.
“EMS can honor any valid physician order”

Do Not Resuscitate  
Continued from page 6

Will EMS honor physician DNR orders that do not meet the properly executed definition of the OHDNR regulation?

EMS can honor any valid physician order. However, first responders may be required by their local EMS protocol to call “medical control” for guidance if the order is not presented on a purple form and signed by both the doctor and the patient or patient’s representative.

Before an actual emergency occurs, providers should communicate with local EMS representatives to determine what policies and procedures are in place regarding DNR orders.
The creation of the Purple Form in law “did not mandate its use, or deligitimize any other legally executed form…"

The law “in no way mandated the use of the form.”

Other provisions in statutes that requires EMS protocols “does not mandate the use of a specific form.”
What is meant by standard of care?

- Operational Standard of Care
- Legal Standard of Care
- Both play part in how care at end of life is managed
Operational Standards of Care

• Formal or informal guidelines for care and treatment that are generally accepted in medical community

• Set by facilities, their medical staffs, professing credentialing bodies.

• For example, types of policies we discuss today regarding TPOPP implementation, help establish operational standard of care for each specific provider
Legal standards of care

• What would the courts think?
• What would reasonable health care provider do under same or similar circumstances?
• Is it malpractice?
• We are talking here about professional conduct
• Legal basis is basic tort law
Another Benefit of Standard of Care

Evolves As Practice of Medicine Evolves
Legislative Remedy for DNR Incomplete

Fails to keep up with operational standards

Focuses solely on rescue medicine as default treatment for everyone

Definitions and decisions about Palliative Care should rely on discussions and considerations by patients and practitioners rather than policy makers - reflecting standard of care.
Refusal of Medical Treatment – Case Law

Cruzan v. Director Missouri Department of Health 497 US 261 (1990)-

The Supreme Court recognized that a competent person has a constitutionally protected liberty interest under the due process clause of the 14th Amendment in refusing unwanted medical treatment that must be balanced against the state’s interest in preserving life.

The Court held that the Constitution does not forbid a state from requiring clear and convincing evidence of an incompetent persons wishes as to withdrawal of life-sustaining treatment and if there were such wishes expressed by the patient when competent, the patient’s rights would outweigh the State’s interests in protecting life
Refusal of Medical Treatment – Regulations: 42 CFR 13(b)

(1) Patients have the right to participate in care plan.
(2) Patients have right to make informed decisions about their care, including right to refuse treatment.
(3) Patients have the right to formulate advance directives
CMS Allows Payment for Advance Care Planning

- Effective January 1, 2016 Timed Based CPT Codes Were Added
- CPT CODE 99497-Advance Care Planning (including Advance Directives) with a Physician or Other Qualified Health Professional (APRNs and PAs)-for the first 30 minute discussion
- CPT CODE 99498-each additional 30 minutes
CMS Instructions

1. No limit to the number of times a code can be billed.

2. CMS would expect to see a documented change in health status of the beneficiary and his/her wishes regarding end of life care when this code is billed multiple times for a given beneficiary.

3. There is no place of service requirement for these codes (includes facility locations and non-facility locations)

4. Expectation is for the billing professional to manage, participate and contribute to the provision of service which means “direct supervision”
Documentation and Billing

Appropriate documentation would include:
A. An account of the discussion
B. Notation that the discussion was voluntary
C. That there was an explanation of advance directives
D. Description of Forms that were considered
E. Who was present for the discussion
F. How much time was spent for the discussion
Join Us

Asses Institutional and coalition readiness

Local coalition formation of key stakeholders in
- Hospital, EMS, LTC, Home Care
- Leadership
- Passion, commitment
- Willing to outreach, educate and participate in performance improvement
- Sustainability

Interdisciplinary Approach
- Facilities: hospitals, SNFs, ALFs, DM programs
- Disciplines: MD, RN, SW, EMS, Atty, consumers
Join Us continued

Contact the Center for Practical Bioethics if you are interested in forming a local coalition: TPOPP@practicalbioethics.org

Register with the Bi-State TPOPP Coalition online--

Ensure Toolkit resources are in place

◦ Check systems readiness
  ◦ Policies in place, medical staff rules addressed, providers aware
  ◦ Workflows and accountability for form management
  ◦ Plan in place for provider data collection
◦ Check facilitator readiness: SW, nursing, MD, chaplain, residents
  ◦ Goal-based, patient-centered discussions, not merely a form
Institutional Profiles

Database and survey platform for clinical and translational research.

TPOPP objectives with Institutional Profile:
- Generating and managing institutional profiles
- Monitoring development of implementation plans
- Evaluating the efficacy of TPOPP
Institutional Profiles

TPOPP involves a diverse group of institutions, each with unique needs and in different stages of implementation.

A periodic survey will generate institution-level profiles to document these details.

The survey “remembers” responses from the previous rounds, so only new developments will need to be added.
Thanks!

Questions and Answers

Matthew Pjecha
TPOPP@practicalbioethics.org
816.979.1366