Uniting Advance Care Planning Conversations – Providers and the Community

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What We Will Cover

I. Basics of Advance Care Planning and MOST Form
II. Introduction to National POLST Paradigm
III. About the North Carolina Partnership for Compassionate Care
IV. Example of a regional coalition effort
Objectives

• Provide an introduction to the North Carolina Partnership for Compassionate Care (NCPCC)
• Educate on resources and initiatives to promote utilization of MOST form and advance directives in North Carolina
• Share the activities of a regional collaboration in promoting awareness, understanding, and use of advance directives in a community

BACKGROUND AND BASICS
Advance Care Planning

Advance care planning involves learning about the types of decisions that might need to be made, considering those decisions ahead of time, and then letting others know about your preferences. These preferences are often put into an advance directive...


Americans want to be involved in decision making...

- 87% believe patients and families should have greater say in treatment options
- 88% say it is important for doctors to be completely honest about family member prognosis
...but feel they don’t currently have control

- Half surveyed believe most in US have too little control over end-of-life care
- Those with fair/poor health feel there is less control (63%)

What people want for their own death

Americans concerned about being a burden, want peaceful and comfortable deaths.

Only 23% say living as long as possible extremely important.
Cultural & Other Priority Differences

Perceptions of care and priorities at end of life vary by demographic & faith groups, cultures.

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Last wishes

What people most want in their final months

Our survey of what matters most at life’s end


Source: Kaiser Family Foundation/The Economist
In-Home & Hospital Deaths

Prefer to die at home: 70%
Actually die at home: 24%*

Prefer to die in hospital: 9%
Actually die in hospital: 35%*

Prefer to die in nursing home: 1%
Actually die in nursing home: 28%*

* CDC/NCHS, National Vital Statistics System, 2007 data for decedents 65 and over

Not Yet Having the Conversation

1 in 10 Report Discussing Their Own End-of-Life Care Wishes With a Health Care Provider

Percent who say they have ever had a conversation with a doctor or other health care provider about their wishes for end-of-life care:

Percent who say they have ever participated in a discussion with a doctor or other health care provider about another family member’s wishes for their care at the end of their life:

SOURCE: Kaiser Family Foundation/The Commonwealth Fund-Capital University Survey of Aging and End-of-Life Medical Care (conducted March 30-May 19, 2004)
Continued Emphasis is Needed

• Difficult to capture broad data on advance directives without statewide registry
  – Registry must be curated to be current
• Medical systems starting to capture – not always accessible
• Varying estimates of # with AD in place:
  – Only 20% to 30% typically report having AD— (Associated Press, 2010)
  – Among those 60 and older, about 50% have AD (Pew, 2006)
  – 88% of hospice patients have AD on record (Jones, 2011)


Barriers to Advance Care Planning

• Lack of awareness
• Denial – attitudes towards death and dying
• Confusion
• Cultural differences

Add: Difficulties having conversations with family, patients, providers

Elements of Advance Care Planning

• Most important: the conversation
  – Discussions with loved ones
  – Health providers
  – Faith leaders

• Advance Directives – legal documents
• Portable Medical Order – POLST or MOST (NC)
• DNR

Advance Directive

• **Documents** written in advance of serious illness that state your choices for health care, or name someone to make those choices, if you become unable to make decisions – *American Hospital Association*

• Typically references legal documents as opposed to medical documents.

An advance directive may include:

- Naming a healthcare agent (via a Healthcare Power of Attorney document)
- Expression of healthcare preferences (living will)
- Both of the above
Portable Medical Order

- A portable medical order is a signed physician order.
- It is made to identify patient wishes regarding treatment in an order that can travel with the patient outside of or between medical facilities.
- MOST (Medical Order for Scope of Treatment), the NC portable medical order, should be considered if a patient is in their last year of life, or if it wouldn’t surprise their provider if they passed away within a year.

NC Form is Medical Order for Scope of Treatment, enacted 2008
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Research - POLST Supports Patient Preferences

- Those with a POLST requesting comfort measures only were more likely to die outside of hospital (6.4%) and in home (48.9%)
- Those with a POLST requesting full treatment were more likely to die in hospital (44.2%) rather than in home (28.0%)
- Fromme, et. al., Association Between Physician Orders for Life-Sustaining Treatment for Scope of Treatment and In-Hospital Death in Oregon, Journal of American Geriatrics Society, 2014
Research on POLST and Hospice - 2017

“Advance care planning with completion of POLST forms compared with ADs in patients with advanced cancer... study suggests that goals-of-care discussions including POLST form completion may improve end-of-life care for patients with advanced cancer.”

“The odds of being admitted to hospice for patients with POLST forms were 2.69 times those of patients with ADs.”

“Association of Physicians Orders for Life-Sustaining Treatment Form Use With End-of-Life Care Quality Metrics in Patients With Cancer”
Journal of Oncology Practice, July 10, 2017

Portable medical orders
DNR vs MOST/POST

A portable DNR order (goldenrod) gives only basic instruction to EMS not to perform CPR. A MOST form includes preferences about not only CPR, but also other patient wishes including intubation, antibiotics, artificial nutrition and hydration. Moving from using the DNR to the MOST form better supports the patient’s goals of care.
COLLABORATIVE EFFORTS TO PROMOTE ADVANCE CARE PLANNING

Definitions:
Three Initiatives

• Federal - National POLST Paradigm
  – National voluntary effort dedicated to advancing the use of Physicians' Order's to ensure patient preferences are honored at end-of-life
  – [www.polst.org](http://www.polst.org)

• State - North Carolina Partnership for Compassionate Care
  – Informal partnership committed to educating and informing about Advance Care Planning and use of MOST Form in NC
  – [www.compassionatecarenc.org](http://www.compassionatecarenc.org)

• Region - Northwest Regional Coalition
  o Regional section of NCPCC
  o Providers and community coalition
  o Developed and use Got Plans? Materials for ACP training
  o [www.gotplans123.org](http://www.gotplans123.org)
The National POLST Paradigm helps patients get the medical treatments they want, and avoid the medical treatments they do not want, when they are seriously ill or frail. It's about helping people live the way they want until they die.

The POLST Paradigm – which stands for Physician Orders for Life Sustaining Treatment - encourages patients and their health care professionals to talk about what patients want at the end of life.

National POLST Paradigm

What is POLST?

Click here to download the article on POLST that clarifies many misconceptions about POLST.

The POLST Paradigm was developed to improve the quality of patient care by creating a system that identifies patients' wishes regarding medical treatment and communicates and respects them by creating portable medical orders. While the POLST Paradigm supports the completion of advance directives, clinical experience and research demonstrate that these advance directives are not sufficient alone to assure that those who suffer from serious illnesses or frailty will have their preferences for treatment honored unless a POLST Form is also completed.

A key component of the system is thoughtful, facilitated advance care planning conversations between health care professionals and patients and those close to them to determine what treatments patients do and do not want based on their personal beliefs and current state of health. In these conversations patients are informed of their treatment options and, if they wish, their health care professional completes a POLST Form based on the patient’s expressed treatment preferences.
Supporting Organizations

• American Bar Association
• The Society for Post-Acute and Long-Term Care Medicine (AMDA)
• AARP Public Policy Institute
• Catholic Health Association
• National Academies of Sciences, Engineering & Medicine, Health & Medicine Division (formerly the Institute of Medicine)
• National Association of Social Workers
• Pew Charitable Trusts

Research and POLST

• Various research studies demonstrate support for the use of POLST:
  – A POLST Form accurately captures individual preferences
  – POLST form results in greater adherence to individual wishes than advance directives alone
  – Hospices found form useful in preventing unwanted medical care and initiating conversations
  – Treatment limitations respected 98% of time
  – POLST form also helps to support receipt of desired treatment

Specific citations for studies at www.polst.org
POLST Care Continuum Toolkit Under Construction

• Reference materials for POLST, resources to implement
• Tailored to provider settings
  – Primary care, EMS, inpatient hospital, nursing home, hospice
• Webinar series available; toolkit under development

www.polst.org/toolkit
What Is NCPCC?

- North Carolina Partnership for Compassionate Care
- Partnership formed to promote Advance Care Planning for the state’s residents
  - Started in 2012 by individuals seeking to engage and inform NC providers and individuals
  - Program of North Carolina Medical Society
  - Program moved to Hospice & Palliative CareCenter for programmatic support 2016
- Recognized NC point of contact for National POLST
- Open forum - sharing of information

Activities of NCPCC

- Promoting/educating on Advance Care Planning & MOST (logo-neutral)
- Efforts to enhance/simplify ACP in NC
- Regional coordination/communication
- Monitoring national developments/POLST
- Source of information on website, links to materials, resources
  - Short form advance directive
  - Information about MOST, DNR, Organ Donation
NCPCC Web Presence

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NCPCC Online Resources

- Selected ACP resources and reference materials
- NC forms – living will, HCPOA, Advance Directive, DNR, organ donation
- MOST – background and sample form, access to e-learning for professionals
- For professionals – Information on Artificial Nutrition and Hydration
- References to training materials
Partnering with NC Bar Association

• 2015 NC Bar program of free Advance Care Planning clinics (10)
• Joint Advance Care Planning efforts began 2016
  – Recognizing National Healthcare Decision Day
  – Pro-bono attorney project "A Gift to Your Family"
  – Got Plans? Workshops
• Joint effort activities:
  – Monthly planning calls
  – Online registration
  – Coordinated marketing/communication plans
• 2016 free clinics in 21 locations
• 2017 free clinics (28 clinics) in 23 locations

Other Activities of NCPCC

• Monitoring National Initiatives
  – Use of electronic POLST and POLST registry in limited states
  – Best practices in legislation, documentation, training
  – Research on effectiveness of POLST, Advance Care Planning
  – Legislative support
• Development of Additional Training Materials
  – Best practice sharing across State
  – Provider versus consumer
• Standards for NC Advance Care Planning materials
  – Regulatory requirements, National POLST criteria, Best practices
• Metrics/Quality Assessment
  – Review of research; identification of appropriate metrics
NCPCC Areas of Focus

- Consumer facing ACP efforts statewide
  - Sharing of best practices
- Promotion of electronic forms and integrated registry
- Best practices for MOST Form
- Simplification for Advance Directives
- Statewide communication and sharing – website, newsletter, meetings

Regional Coalitions to support activities statewide:

- Varying degrees of activity
- Monthly telephone discussions
- Open exchange and support
Northwest Region Coalition

REGIONAL COALITION EXAMPLE

• Longstanding provider collaboration at some level
• Standing meetings in Winston-Salem
  – Open to any/all who are interested
• Topics can vary depending on need, attendees
• Attendees have included: Major medical centers, hospices, EMS providers (community paramedicine), VA local contacts, MD groups, community care networks, faith leaders
• Key outcome – Got Plans?
Got Plans?

• Initiative of regional coalition
  – Novant Health, Wake Forest Baptist Health, Hospice & Palliative CareCenter and others
  – Materials meet state guidelines and best practices
  – Part of efforts of both major health systems in the area
    • Working to align and increase awareness for internal and external audiences
• Primary deliverables: website and workshops
  – Website: gotplans123.org
  – Workshops on Tuesdays – every month, every week
Regional Coalition – Addressing Local Need

Coalition Sharing

• Training models - what’s working and what’s not (community solutions)
• How to integrate EMR’s
• Bringing EMS to the conversation
• Collaborations for the community
Collaboration
The Red Sleeve Pilot

- Red transparent document sleeve for patient MOST form
- Clips in chart when inpatient
- Protects form when outpatient, can hang on refrigerator or over the bed
- Unbranded to bridge gaps across various systems
- Ensures documents stay with patient

A System’s Perspective
Benefits of Collaboration

- Unifying message to community (culture change)
- Collaboration to drive policy change
- Prioritization of limited resources
- Connection to National POLST paradigm
- Access to subject matter experts
Selected References

- www.polst.org (National POLST Paradigm)
- www.polst.org/resources (references for research articles, legal analyses, etc.)
- www.compassionatecarenc.org (North Carolina Partnership for Compassionate Care – Healthcare Professionals resources page)
- www.gotplans123.org (Got Plans? Materials/workshops)