

Supporting the Patient Voice: Building the Foundation of Shared Decision-Making

By Patricia Bomba

Early engagement is important in shared decision-making about care: some programs have successfully improved documentation and clinical application of these care decisions.

Throughout their lives, patients are frequently faced with making complex medical decisions requiring them to choose between many options, to face uncertain outcomes, and to weigh the potential benefits and harms of treatment—all decision-making components that are valued differently by each individual. But at no time is shared decision-making more important than near the end of life.

It is important to move the shared decision-making process on care choices upstream and use it consistently over the life course.

Shared decision-making is neither clearly nor consistently defined in the research literature (Institute of Medicine [IOM], 2014). However, the essence of shared decision-making moves medical decision-making from the extremes of paternalistic, physician-centered

beneficent decisions and patient-autonomous decisions to a person-centered model in which the physician and patient share the process.

For persons who are seriously ill and might die within a year, making life-and-death decisions to withhold and-or withdraw life-sustaining treatment requires thoughtful discussions and shared medical decision-making that is done within scope of practice. To best employ a shared approach for making complex medical decisions, it is important to move the process upstream and use it consistently throughout the course of a patient's life.

Moving Shared Decision-Making Upstream

The national Choosing Wisely campaign demonstrates one attempt to move shared decision-making upstream. The American Board of Internal Medicine (ABIM) Foundation in 2012 rolled out Choosing Wisely to promote conversations between physicians and patients that would help avoid unnecessary testing and medical

→ABSTRACT Shared decision-making is critical to a model of care that places the person at the center of treatment decisions, from birth to death. To ensure an individual's treatment preferences are honored at the end of life, shared decision-making must be person-centered and well-informed. Physicians and other clinicians must be trained, comfortable with necessary discussions, and act within their scope of practice. Similarly, the patient and-or other medical decision-maker must be prepared to actively participate in the process. A multidimensional community approach to advance care planning is essential. | **key words:** *end-of-life care, shared decision-making, advance care planning, POLST, eMOLST, MOLST*

expenses (Wolfson et al., 2014). Some estimates suggest that as much as 30 percent of all health-care spending is wasted (Berwick, 2012).

While the initial focus of *Choosing Wisely* was on overuse of medical resources, the campaign also emphasizes treatments that place patients at risk for harm, and aims to help make sure patients get safe, high-quality care (Cassel and Guest, 2012). Patients are encouraged to consult with their physicians and, through shared decision-making, “choose care that is supported by evidence, not duplicative of other tests or procedures already received, free from harm, and truly necessary” (ABIM Foundation, 2016).

The principles of shared decision-making are well-documented. While there is some guidance about how to approach shared decision-making in routine clinical practice, it is not well-integrated into current clinical practice (Elwyn et al., 2012). From personal clinical experience, a practical approach is to consistently apply a simple framework for shared decision-making, integrating the person’s health status and prognosis, and asking the following questions:

- Will the treatment make a difference?
- What are the benefits and burdens? Or, how might the treatment help and how might it be harmful?
- Is there hope for recovery? If so, what will life be like afterward?
- What does the person value? What matters most and makes life worth living? What are the person’s goals for their medical care?

These key questions can also apply to making decisions about wellness activities, medications, non-pharmacologic interventions, blood work, diagnostic and imaging studies, and life-sustaining treatment. Simply frame the questions around the area of decision making; e.g., ask “Will quitting smoking make a difference?” and follow up with the additional questions, as listed above.

If clinicians can integrate the shared decision-making process as part of their routine practice, this will enhance their ability to use the

model for persons with advanced illness who might die within a year. Arriving at final decisions may require a series of thoughtful discussions, which can be supported by decision aids, such as the “Benefits and Burdens of Tube Feeding/PEG Placement” (Monroe County Medical Society, 2014).

Making Decisions About Life-Sustaining Treatment

Shared medical decision-making for patients with advanced illness is a key component of person-centered, family-oriented healthcare—care that combines chronic disease management with the key pillars of palliative care, including advance care planning, pain and symptom management, and caregiver support integrated with psychosocial, religious, and spiritual care. It is a process in which physicians, at times in collaboration with other clinicians (such as nurse practitioners), and patients work together to make decisions. Early steps in this process include ensuring the patient has the capacity to make the decision, and clearly understands his or her current health status and prognosis.

The shared decision-making process is especially important toward the end of life, when one’s ability to make medical decisions may diminish for a short period of time due to acute illness, delirium, etc., or permanently, because of dementia. Due to the sensitivity of the decisions to be made and the risk of incapacity, the process must also be family-oriented: family members, loved ones, and the person’s designated medical decision-maker must know his or her values, beliefs, goals for care, and preferences for treatment.

Tests, treatments, and care plans are selected based on clinical evidence that balances benefits, risks, and expected specific treatment outcomes in light of the patient’s current health status and prognosis, and take into consideration his or her values, beliefs, and care goals.

It is important to recognize that making complex medical decisions is difficult for indi-

viduals, even for those with medical training, and especially for patients who are near the end of life.

Thus, the physician may offer an opinion to help with decision making when it is medically complex, as long as it aligns with the person's goals for care. Physicians are not obliged to offer treatments that will not work; for example, physicians should not offer trials of Bilevel Positive Airway Pressure to a person with end-stage dementia.

'Physicians are not obliged to offer treatments that will not work.'

Furthermore, physicians must honestly and compassionately share medical evidence that affirms a treatment is unlikely to work and-or will cause more harm than good. For example, there is consensus about the recommendation to avoid use of feeding tubes in persons with advanced dementia (Fischberg et al., 2013). Additionally, cardiopulmonary resuscitation (CPR) is intended to prevent sudden, unexpected death. CPR is not indicated in cases of terminal, irreversible illness where death is expected, or in medical situations where CPR is deemed ineffective. Survival rates after a cardiac arrest are poor (less than 1 percent) in persons with advanced illness, such as end-stage heart failure or metastatic cancer, due to the underlying disease and not the failure of the intervention. Even if the patient survives, there is likely to be significant impairment.

Difficulty in decision making arises when recovery cannot be predicted. In this case, a short-term trial of life-sustaining treatment may be desired. These trials must begin with clarifying the patient's goals for care and require active discussions between the physician and the patient about the most appropriate course of treatment. Goals for care often evolve from a focus on longevity, to functionality, to comfort care.

Consider a woman with end-stage chronic obstructive lung disease with multiple admis-

sions for respiratory failure requiring intubation and mechanical ventilation. During her last admission, she had difficulty being weaned off the ventilator. She does not want to be dependent on a ventilator to live, but hopes to see the birth of her first grandchild, anticipated in three months. The woman expressed her preference for another trial of intubation and mechanical ventilation should she experience acute respiratory distress due to a bout of pneumonia or congestive heart failure. If a trial is not effective, she would not want a tracheostomy. Her goals for care should be discussed again after the birth of her grandchild, and to clarify how her treatment preferences may or may not change.

If the treatment is no longer beneficial, it is legally and ethically appropriate to discontinue such treatment, recognizing it is the underlying disease, not the act of withdrawing treatment, which causes death. There is no medical, legal, or ethical distinction between withholding and withdrawing life-sustaining treatment. If such a distinction existed in the clinical setting, a patient might refuse treatment that could be beneficial, out of fear that once started, it could not be stopped.

Shared Decision-Making When the Person Lacks Capacity

Each individual has the right to make his or her own medical decisions (U.S. Congress, 1990). If the individual is unable to make medical decisions, the designated medical decision-maker must make healthcare decisions in accordance with the person's wishes, including the person's religious and moral beliefs. Designated medical decision-makers are called health care agents, proxies, power of attorney for health care, or surrogates in different state-specific advance directive documents (National Hospice and Palliative Care Organization, 2016). In this article, the term "health care agent" is used to indicate an individual designated in an advance directive, which is called a "health care proxy." A "surrogate" is a person who, by default, becomes

the decision maker for an individual who has no appointed health care agent.

The primary purpose of creating a legal document like a health care proxy is to extend patient autonomy beyond the loss of decision-making capacity. Health care agents are appointed to advance the wishes and values of the patient, not to disregard them and substitute their own wishes and values when participating in shared decision-making (Bomba and Karmel, 2015).

Different states have different laws governing end-of-life decision-making (National POLST Paradigm Task Force, 2014). For the purpose of this article, the legal requirements that embody the ethical framework for making decisions regarding life-sustaining treatment under New York State Public Health Law (NYSPHL) will be used for illustrative purposes.

As per NYSPHL, a person is presumed to have the capacity to make his or her own decisions, unless a physician assesses the person and determines that he or she is unable to make a specific medical decision; this determination must be confirmed by a second physician (Bomba and Karmel, 2015). Variation in state public health law may define who can determine capacity. Without regard to the variations, the clinician should be trained and qualified, as clinicians must be able to assess a patient's capacity early in the process of shared decision-making. Capacity training is an integral component of New York's clinician training on advance care planning.

Capacity is the ability to take in information, understand its meaning, and make an informed decision using that information. Intact capacity permits functional independence. Capacity requires a cluster of mental skills people use in everyday life and includes memory, logic, the ability to calculate, and the innate flexibility to turn attention from one task to another.

Medical determination of capacity often is difficult; and there is no standard tool with which to do this. Capacity assessment is a com-

plex process and is not simply determined by the Mini-Mental Status Exam. Assessments should involve a detailed history from the patient and collateral history from family; a focused physical examination, including cognitive, function, and mood screens; and appropriate testing to exclude reversible conditions that may affect the ability to make decisions.

Capacity requirements vary by task. The capacity to choose a trusted individual as an appropriate health care agent differs from the capacity to agree to a medical procedure or treatment. The ability to make medical decisions may vary based upon treatment complexity. An individual may be able to make simple healthcare decisions or request palliation and relief of pain and suffering, but may be unable to make complex decisions regarding cardiopulmonary resuscitation and life-sustaining treatment.

Because the health care agent will make medical decisions if the person loses his or her capacity to make such decisions, the health care agent should be part of the discussion and must abide by the person's decisions. Additionally, if the individual loses the ability to make complex decisions with worsening health status and prognosis, prompting a change in the goals for care, medical decisions to forego specific life-sustaining treatment documented as medical orders must be followed and cannot be changed by a designated health care agent. However, the health care agent can make additional treatment decisions to withhold and-or withdraw life-sustaining treatment consistent with the person's values, beliefs, and goals for care.

Advance Care Planning as a Wellness Initiative

Advance care planning is a process of planning for future medical care in the event that an individual is unable to make his or her own medical decisions. Advance care planning assists an individual in preparing for a sudden unexpected illness or injury (from which an individual may recover), as well as the dying process and,

ultimately, death. The introduction of advance care planning as a communication process when a person is healthy and well and-or earlier in the patient’s disease course can also improve shared decision-making, specifically by framing advance care planning as a wellness initiative.

The advance-care-planning process should result in a legal document called an advance directive. There are two types of advance directives: the health care proxy (also known as the durable power of attorney for health care) and the living will. The critical document is the health care proxy. The key issues to consider include choosing the right health care agent, clarifying values, beliefs, and goals for care, and having a meaningful conversation with the agent, family, loved ones, and caregivers, as well as with primary and specialty physicians involved in the person’s care. These issues are

consistent with a key recommendation for public education and engagement found in the IOM report, *Dying in America* (IOM, 2014).

Initiating advance care planning is relevant at all ages, as no one is immune from acute illness, injury, complex chronic conditions, or death. For all adults, advance care planning should begin at age 18. Improving communication and advance care planning is critically important for individuals of all ages, including adults, adolescents, and children. While children younger than age 18 cannot complete a health care proxy, seriously ill children may have the capacity to participate in shared decision-making and should have the opportunity to do so (NQF, 2006; IOM, 2014). From a population health perspective, encouraging advance-care-planning discussions should be integrated into key life milestones; for example, when applying

Table 1. What to Keep in Mind When Choosing a Health Care Agent

Meet legal criteria (be a competent adult, at least 18 years old)
Be willing to speak on behalf of the person
Be willing to act on the person’s wishes
Be able to separate his/her own feelings from those of the person
Live near the person or be willing to come to that geographical location, if needed
Know the person well
Understand what values, goals, and morals are important to the person
Be willing to discuss sensitive wishes
Be willing to listen to wishes expressed by the person
Be willing and able to work with those providing care to the person to carry out those wishes
Intend to be reasonably available in the future
Be able to handle potential conflicts between the family and close friends of the person
Be willing and able to handle the responsibility of carrying out end-of-life wishes
If chosen as an alternate, be willing and able to act if the primary HCA is unwilling or unable to act

Source: Community Conversations on Compassionate Care Advance Care Planning booklet. Copyright, Excellus BlueCross BlueShield, used with permission.

for a driver's or marriage license, or matriculating to college, etc. (IOM, 2014).

Community Conversations on Compassionate Care program

The Community Conversations on Compassionate Care (CCCC) (goo.gl/4BFDOJ) program launched in 2002 to encourage early advance-care-planning discussions and the completion of advance directives, particularly healthcare proxies, and has yielded positive outcomes (Bomba and Orem, 2015). CCCC combines storytelling and behavioral readiness theory outlined in “Five Easy Steps” for completing the process. The program focuses on choosing the right health care agent, as outlined in Table 1 (see page 25), and sharing personal values, beliefs, and goals for care. The CCCC program encourages individuals to learn to make medical decisions upstream by employing a shared decision-making model that uses the four key questions noted at the beginning of this article.

National POLST Paradigm

While advance directives are key legal documents, medical personnel cannot interpret and follow them in an emergency, as they may not

apply in the current clinical situation. However, emergency medical personnel can follow medical orders. Persons with advanced illness who might die in the next year and-or are of advanced age may also work with their physician to complete the process that results in a Physician Orders for Life-Sustaining Treatment (POLST) Paradigm form.

Completing a POLST form is a clinical process designed to facilitate discussion between the physician and the patient and his or her family, loved ones, and caregivers; other members of the care team can participate in the process within scope of practice. A POLST form creates a set of actionable medical orders that all healthcare providers, including EMS personnel, must follow in all settings. A key feature of POLST is that it is based on the patient's current health status, prognosis, and goals. This is a critical difference between an advance directive and a POLST. Since a POLST is completed for current treatment, the burden of making these decisions is lifted off of family members. (See Table 2, below, for a detailed chart that shows the differences between Advance Directives and POLST [Bomba, Kemp, and Black, 2012]).

Table 2. Differences Between POLST and Advance Directives

Characteristics	POLST	Advance Directives
Population	For the seriously ill	All adults
Timeframe	Current care	Future care
Who completes the form	Healthcare professionals	Patients
Resulting form	Medical Orders (POLST)	Advance directive
Health care agent or surrogate role	Can engage in discussion if patient lacks capacity	Cannot complete
Portability	Provider responsibility	Patient/family responsibility
Periodic review	Provider responsibility	Patient/family responsibility

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Table 3. The 8-Step MOLST* Protocol**1. Prepare for discussion:**

- Review what is known about patient and family goals and values
- Understand the medical facts about the patient's medical condition and prognosis
- Review what is known about the patient's capacity to consent
- Retrieve and review completed Advance Directives and prior DNR documents
- Determine who key family members are and, if the patient does not have the capacity, see if there is an identified health care agent, guardian, or healthcare representative
- Find uninterrupted time for the discussion

2. Begin with what the patient and family know:

- Determine what the patient and family know regarding condition and prognosis
- Determine what is known about the patient's views and values in light of the medical condition

3. Provide any new information about the patient's medical condition and values from the medical team's perspective:

- Provide information in small amounts, giving time for response
- Seek a common understanding; understand areas of agreement and disagreement
- Make recommendations based on clinical experience and in light of the patient's condition

4. Try to reconcile differences in terms of prognosis, goals, hopes, and expectations:

- Negotiate and try to reconcile differences; seek common ground; be creative
- Use conflict resolution when necessary

5. Respond empathetically:

- Acknowledge
- Legitimize
- Explore (rather than prematurely reassuring)
- Empathize
- Reinforce commitment and non-abandonment

6. Use MOLST to guide choices and finalize patient and-or family wishes:

- Review the key elements with the patient and-or family
- Apply shared medical decision-making
- Manage conflict resolution

7. Complete and sign MOLST:

- Get verbal or written consent from the patient or health care agent, guardian, healthcare representative
- Get written order from the treating physician and witnesses
- Document conversation

8. Review and revise periodically

*MOLST is a medical order form designed to provide a single, community-wide document that would be easily recognizable and enable patient wishes for life-sustaining treatment to be honored. This 8-Step Protocol was originally developed by Dr. Patricia Bomba for the MOLST Program of New York State. Program information is found at www.CompassionandSupport.org. Copyright, Patricia Bomba, M.D., M.A.C.P., Excellus BlueCross BlueShield, used with permission.

The IOM report, *Dying in America*, recommends implementing policies and payment systems to support high-quality end-of-life care, including “encouraging states to develop and implement a Physician Orders for Life-Sustaining Treatment (POLST) paradigm program in accordance with nationally standardized core requirements” (IOM, 2014). State programs are in various stages of development; the latest information is accessible on POLST.org. POLST forms are state-specific and vary based on individual state needs and regulations. State programs vary in name (e.g., Medical Orders for Life-Sustaining Treatment [MOLST]; Clinician Orders for Life-Sustaining Treatment [COLST]; Medical Orders for Scope of Treatment [MOST]; Physician Orders for Scope of Treatment [POST and POLST]), as well as in how they are de-

signed, managed, and executed (National POLST Paradigm Task Force, 2014).

Ensuring Accessibility to Properly Completed POLST Forms

New York is a founding state of the National POLST Paradigm Task Force. The program in New York, called MOLST, meets the nationally standardized core requirements for POLST Paradigm programs. Development began as a community initiative in 2001 to address consumer concerns that advance directives were not being followed.

MOLST focuses on quality of the process

In accordance with the National POLST Paradigm, New York’s MOLST focuses on the quality of the conversation, documentation of the

Table 4. A Multidimensional Approach to Effective NY MOLST & eMOLST Implementation

Culture change*
Professional training of physicians, clinicians, and other professionals*
Public advance-care-planning education, engagement, and empowerment*
Thoughtful discussions*
Shared, informed medical decision-making*
Care planning that supports MOLST
System implementation, policies and procedures, workflow
Dedicated system and physician champion in all community settings
Leverage existing payment stream (CPT codes 99497 and 99498) to encourage upstream shared, informed, decision-making*
Standardized interoperable online completion and retrieval system available in all care settings to ensure accuracy and accessibility (e.g., NYSeMOLSTregistry.com)*
In the future: sustainable payment stream based on improved compliance with person-centered goals, and preferences for care and treatment, measured by: <ul style="list-style-type: none"> ▪ improved resident/family satisfaction ▪ reduced unwanted hospitalizations

*These recommendations were affirmed and/or recommended in the 2014 IOM report, *Dying in America*. Copyright, Patricia Bomba, M.D., M.A.C.P., Excellus BlueCross BlueShield, used with permission.

clinical process, and following the ethical and legal framework for making end-of-life decisions to ensure access to a properly completed MOLST form. The need for a standardized clinical process was recognized with early implementation efforts. The 8-Step MOLST Protocol outlined in Table 3 (see page 27) was introduced in 2005 and revised in 2011 to comply with significant changes in NYSPHL (Bomba, 2011). It is easily adapted for any state's POLST Paradigm program. Seven legal requirements checklists in New York support the clinical process to ensure the shared decision-making process is completed correctly (New York State Department of Health, 2013).

Medical personnel cannot interpret and follow advance directives in an emergency, as they may not apply to the current clinical situation.

Early on, New York envisioned creating a registry and an electronic version of the MOLST form and process. New York's eMOLST system, accessible at NYSeMOLSTregistry.com, incorporates MOLST form completion, MOLST process documentation, and also serves as a registry of MOLST forms for New York State. The online MOLST completion system provides a standardized clinical process, the ethical and legal framework to document personal values, beliefs, and goals for care that in turn drive the choice of the life-sustaining treatments individuals wish to receive and/or avoid at that point in time. The eMOLST system also includes embedded educational links and videos that physicians and other clinicians can use as part of the discussion. Quality assurance is built in with logic-based coding to ensure an eMOLST form created in NYSeMOLSTregistry.com is completed with 100 percent accuracy.

The eMOLST system allows clinicians to print forms to integrate with paper records, or the Web-based application can be electronically

integrated with an electronic medical record. The eMOLST system provides access twenty-four hours a day, seven days a week to eMOLST forms for any provider with access to the registry. The program is designed to improve clinical outcomes, legal outcomes, provider satisfaction, and meet the needs of health systems seeking to reduce patient harm and achieve the Triple Aim.

With fifteen years of consistent leadership, New York has addressed challenges and shared best practices and lessons learned with other states and national leaders. Effective implementation of MOLST and eMOLST requires a multi-dimensional approach as outlined in Table 4 (see page 28).

Conclusion

The key recommendations in the IOM report, *Dying in America*, support a care model for shared decision-making that begins with early advance-care-planning discussions and completion of healthcare proxies (IOM, 2014). Use of a shared decision-making model over the course of a person's lifetime will engage and empower the individual and prepare him or her and his or her family for end-of-life decision-making focused on "what matters most." A multi-dimensional approach is needed to ensure accessibility to properly completed and documented POLST Paradigm forms. New York's approach includes implementation of eMOLST supported by physician or clinician training and public education to ensure well-informed, effective shared decision-making. 🌿

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