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Virginia POST: Improving Patient- Physician Communication about End of Life Care

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Case Study

Virginia POST: Improving Patient-Physician Communication about End of Life Care

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Educational Objectives

1. Examine the complexities of medical decision-making at the end of life and the inadequacy of advance directives alone to affect care at the end of life.
2. Demonstrate how effective communication can facilitate medical decision-making and improve congruency between care received and patient goals, priorities, and values.
3. Discuss the National POLST Paradigm and the current status of POST in Virginia.

Introduction

"But my patient has a living will and a medical power of attorney. Isn't that enough?" The answer is, "Probably not." It is our intention to explain what Virginia's POST (Physician Orders for Scope of Treatment) is and how it came to be, noting its origins in the POLST Paradigm (Physician Orders for Life-Sustaining Treatment). Both the POST and POLST processes are intended to prompt timely advance care planning discussions for people who have progressive serious illness.

Background

A POST or POLST is a signed physician's order for medical care that follows, reflects, and implements a patient's wishes about his or her health care. A patient's physician writes the POST based on the patient's wishes, as identified in discussions that include the patient, the family, and the physician or a trained advance care planning facilitator. POST provides a framework for care-providers to put in place orders that ensure that seriously ill patients with life-limiting illnesses or advanced frailty receive the treatment they want and avoid the treatments they do not want.

Despite the intent of living wills to provide autonomy for patients beyond their ability to direct their care, living wills alone have generally failed to achieve a difference in care at the end of life (Fagerlin & Schneider, 2004). This should come as no surprise. The premise that an uninformed patient should be able to conjure up medical decisions for a hypothetical future event with unidentifiable maladies and unpredictable treatments is unreasonable. Even patients and families with contemporary decisions about current illnesses can be overwhelmed by the medical decision-making process. Medical advances will likely further exacerbate the situation in the future.

Examining end-of-life care in this country, we find a number of problems with and barriers to providing care that is aligned with the patient's wishes. In addition to the problem of a living will not providing enough guidance to the clinician at the bedside, there is also the problem of the advance directives not being reviewed and updated as the patient's medical condition changes. Additionally, advance directives are often not available to clinicians at the time that medical care is delivered.

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Assuming there are advance directives, frequently clinical staff within a facility do not know what and where a patient's advance directives are. It is also uncommon that the patient's written advance directives will follow the patient to another health care setting. Often, a transferring facility will fail to communicate patient's end-of-life care wishes and medical orders to the transport crew or the receiving facility.

Our current system of end-of-life care often fails to plan ahead for contingencies. If a patient loses decision-making capacity and the medical condition deteriorates, it is likely that he or she will be transferred to a hospital and possibly receive over-treatment and have unnecessary pain and suffering. If the patient has a DNR (do not resuscitate) order and loses decision-making capacity before orders are given for specific end-of-life care, the staff will likely assume that the patient would not want more than comfort measures, in which case the patient may be under-treated relative to his or her wishes, which were never elicited and/or communicated.

Research has verified that families caring for a seriously ill person nearing death are at risk for complicated grieving. That risk is compounded if they are forced into making complex decisions about medical care without being adequately prepared or informed about their loved one's preferences. The task of decision-making trumps the more critical need to tend to the emotions and extraordinary stress of losing a loved one (Wright, et al. 2008; Wendler & Rid, 2011).

History of National POLST

The POLST Paradigm originated in Oregon in 1991after recognizing that advance directives were inadequate for patients with severe, chronic, and terminal conditions. A group of stakeholders developed a new tool for honoring patients' wishes for end-of-life treatment. After several years of evaluation, the program became known as Physician Orders for Life-Sustaining Treatment (POLST).

Although the POLST Paradigm began in Oregon, it quickly spread to other states, which tailored the paradigm to fit their unique legal, medical, and cultural contexts. Among the first states to develop POLST Paradigm programs were New York, Pennsylvania, Washington, West Virginia, and Wisconsin. These states, and others, have become leaders in improving the POLST paradigm and demonstrating its importance in achieving patient-centered outcomes.

The National POLST Paradigm is an approach to end-of-life care planning that emphasizes patients' wishes about the care they receive. It is both a method of planning for end-of-life care and a specific set of medical orders that ensure patients' wishes are honored. The POLST Paradigm is built upon conversations between patients, loved ones, and health care providers, during which patients can determine the extent of care they wish to receive. As a result of these conversations, patients may elect to create a POLST form, which translates their wishes into actionable medical orders. The POLST form assures patients that medical providers will provide only the care that patients themselves wish to receive, and decreases the frequency of medical errors.

POLST is not for everyone. It complements but does not replace other advance directives that patients complete. It is most appropriate for people who are seriously ill with life-limiting (also called terminal) illnesses or advanced frailty characterized by significant weakness and extreme difficulty with personal care activities. For healthy patients, an advance directive is an appropriate tool for making future end-of-life care wishes known to loved ones.

Case Study #1

Mr. Jan was 71 years old with severe COPD and mild dementia. He was convalescing at a skilled-nursing facility after a hospital stay for pneumonia when his shortness of breath worsened and his level of consciousness decreased over 24 hours. The nursing facility staff called EMS who found Mr. Jan unresponsive and with poor respiratory function. Although Mr. Jan had discussed his desire to forgo aggressive, life-sustaining measures with his family and nursing personnel, the nursing facility staff did not document his preferences, inform the emergency team about them, nor mention his do-not-resuscitate order.

EMS wasn't able to intubate him at the scene. They inserted an oral airway, bagged him and transported him to a hospital emergency department. Mr. Jan remained unresponsive and was found to have marked respiratory compromise and be in respiratory acidosis. The emergency department physician wrote, “full code for now, status unclear.” The staff intubated and sedated Mr. Jan and transferred him to the intensive care unit (Lynn & Goldstein, 2003).

This case illustrates the need for an enhanced system of advance care planning which: builds upon a person’s advance directives (most often created when a person is relatively healthy); provides for more focused advance care planning discussions if a person’s chronic illness or medical frailty worsen; and then translates the person’s values, goals, and wishes for end-of-life care into actionable medical orders which serve as a communication tool to be honored across health care settings.

Key Research about POLST

Unlike research on Living Wills, which has not demonstrated an impact on care received, the POLST Paradigm has substantial peer reviewed literature documenting its effectiveness. For example, a study of nursing homes in Oregon, West Virginia, and Wisconsin, which set out to determine how frequently treatment is consistent with wishes recorded on a POLST form, found that patient wishes recorded on a POLST form are honored 94% of the time in the facilities studied (Hickman, et al., 2011).

Research to evaluate differences in outcomes between POLST conversations and traditional methods of communicating treatment preferences indicated that patients with POLST forms had a greater number of recorded end-of-life care preferences and were less likely to have orders for life-sustaining interventions against their preferences (Hickman, et al., 2010).

Perhaps the most revealing data on the POLST Paradigm were presented in a *JAMA* research letter (Fromme, et al., 2012) reporting findings from Oregon that assuage the unfounded concern of some that the PO(L)ST form is biased toward steering patients to limit care. Researchers, analyzing all active forms signed and submitted from December 2009 through December 2010, investigated the populations using the POLST registry and compared the preferences for treatments among persons with DNR orders and those with attempt CPR orders. There was significant heterogeneity in orders, meaning that many patients, including those who did not want to be resuscitated, chose to have additional limited or full interventions and/or tube feedings. Clearly, the POLST form is a neutral form and meets the intent of honoring the freedom of persons with advanced illness or frailty to have or limit treatment. Another critical implication of these results is that a DNR order alone is a poor predictor of the medical care that dying patients want. It is not uncommon for health care professionals to assume that patients who do not want to be resuscitated would choose to have only comfort measures (Fromme, et al., 2012).

The POST Process

The POST process in Virginia, based on the POLST Paradigm, originated in the Roanoke Valley in December 2009 and now is being piloted in 10 regions in the state. The Virginia POST Collaborative, a diverse group of health care, legal, legislative, advocacy, and lay members, is aiming to become endorsed by the National POLST Paradigm. This endorsement means that our POST process and form are available as a uniform, legal, and portable communication tool; one that is recognized as the standard of medical care for advance care planning for people who are seriously ill with life-limiting (also called terminal) illnesses or advance frailty characterized by significant weakness and extreme difficulty with personal care activities. The Medical Society of Virginia in 2012 passed a resolution to support efforts that lead to the recognition and adoption of the "Physician Orders for Scope of Treatment (POST) form as a uniform, portable and legal document in the Commonwealth of Virginia."

POST, like POLST, can be used to guide decisions to attempt CPR and decisions about other medical interventions such as hospitalization, antibiotic use, and artificially administered nutrition and hydration. The physician signs the form and notes with whom it was discussed and the care setting where it originated. The patient (or his or her authorized representative) signs the form to document consent to the orders.

POST provides a framework for crucial conversations among the patient, the family, and the health care providers about goals of care and intensity of care. The POST process guides the conversation, increasing the likelihood that patients will express their wishes and have those wishes honored. After the provider reviews the patient's goals, the choices on the POST form allow a patient to document specific decisions. The patient may choose either less or more invasive treatment and begin to consider each treatment individually in terms of its benefits and burdens. The POST then translates these patient decisions into a signed physician's order that reflects the patient's wishes regarding the treatment they want and the treatment they want to avoid.

"POST is designed to honor the freedom of persons with advanced illness or frailty to have or to limit treatment across settings of care" (Tolle, 2013). POST is entirely voluntary, for no one has to complete a POST; it provides the choice to have or to limit treatments. A POST form may be revoked or changed at any time; comfort measures are always provided. The POST system of communicating patients' wishes for end of life care is the "last step" along the continuum of advance care planning: a continuum that should begin with a young, healthy adult completing his or her advance directive, then continues with the individual updating that advance directive periodically until such time as the individual is diagnosed with advanced illness or frailty. At this point, a POST advance care planning discussion should take place which results in completion of a POST form to reflect his or her preferences and care needs based on the current medical condition. If health status changes, the POST form is reviewed and, if necessary, a new one is completed to reflect the change in the patient's wishes for care. All along this continuum of advance care planning, the goal is to have the conversation before the crisis, and have a communication tool to convey these wishes across care settings.

Quality Improvement Data in Virginia

The first POST pilot project was conducted in the Roanoke Valley. Between December 2009 and May 2011, nearly 100 residents in two nursing homes had completed POST forms. The Roanoke pilot group conducted quality improvement chart reviews of these patients with POST forms in order to determine the congruency of POST orders with the care delivered. The project found that POST orders were congruent with care in about 98% of the cases, a figure slightly higher than congruency figures in a large national study (Hickman, et al., 2011).

This pilot study found that 75% of the residents were never transferred to another care setting during this 18 month period. Of those who were transferred, three went to the emergency department for evaluation and then returned to the facility, one went to an assisted living facility, and two were admitted to the hospital for symptom control. Of the latter, one returned to the nursing home and the other died in the hospital on the oncology unit. One resident was transferred to a Palliative Care Unit at a nearby medical center.

From additional data provided by one participating facility, we were able to compare the final place of care for patients with and without POST forms who died during these 18 months. We found that 25% of patients <u>without</u> a POST form died in an acute care setting in a hospital. All of the patients who died and had a POST form had requested Comfort Measures, which included not being transferred to the hospital; of these patients with POST forms, all died in the facility, or, if transferred, died in either assisted living, home with hospice, or an inpatient palliative unit. None died in a hospital.

Let's take a look at a case in Virginia which illustrates how POST prevents situations like Mr. Jan's and leads to patients receiving the care they want and not receiving care they don't want. This case will also demonstrate how the POST process and form are a catalyst for timely and substantive advance care planning discussions.

Case Study #2

Mrs. West was a 92-year-old widow who lived on a long-term care unit at a large nursing care facility in Virginia. She had chronic renal disease, heart failure, diabetes, hypertension, and a recent stroke. Her heart failure and renal disease were progressing, making it clear that she was not likely to live more than a year. A social worker at this facility, trained as a POST Advance Care Planning Facilitator, informed Mrs. West and her daughter that they could avail themselves of a process of advance care planning that would result in a doctor's order sheet that would serve as a communication tool both within and outside the facility. The daughter, who had Mrs. West's medical power of attorney, was particularly interested because her brother tended to press their mother to have more interventions than Mrs. West wished. In the

POST Advance Care Planning session, Mrs. West said she did not want to be resuscitated when she stopped breathing and her heart stopped beating. She added that, in addition to aggressive comfort measures, she wanted some limited medical interventions, such as cardiac monitoring, less invasive airway support, and transfer to the hospital, if indicated, but asked that health care providers avoid putting her in the ICU. Mrs. West's primary care physician reviewed the POST orders with Mrs. West and her daughter and signed the form to activate the orders.

Shortly thereafter, Mrs. West developed fluid retention in her abdomen and her lower extremities. Her physician, not certain if this was due to her known chronic illnesses, recommended sending her to the hospital emergency department (ED) to be evaluated. The daughter did not want her mother to go to the hospital, but Mrs. West consented to her doctor's recommendation. She was admitted to the hospital after evaluation in the ED. The hospitalist urged her to go on dialysis. Mrs. West adamantly refused but the hospitalist persisted. The daughter called the nursing home social worker who supported their decision and encouraged them to be firm and clear with the hospitalist. The daughter repeatedly assured the hospitalist that they'd thought this through in the POST advance care planning process. Mrs. West summed it up, "I'm 92 years old. I've lived a long and good life. I don't want to spend the rest of my life dependent on being hooked up to a dialysis machine. If this is all you have to offer me, then I don't need to be at the hospital. I want to go back to the nursing home where I live."

Mrs. West returned to the nursing home two days later and the POST form was reviewed, voided, and a new one completed with the change from "Limited Medical Interventions" to "Comfort Measures." Mrs. West was moved to a palliative care room and hospice became involved. She died comfortably three weeks later.

Mrs. West's case illustrates how proactively and effectively the POST Advance Care Planning discussion helped her think through, identify, and communicate her values and goals of care to her family and to those providing her medical care. It beautifully highlights that the advance care planning process is dynamic and fluid. As a person's medical condition changes, it's necessary to review the POST form and see if the person's wishes for treatment have changed.

Summary

POST/POLST can help to clarify and resolve what can be a confusing, even frightening time, a time of urgent, competing, and well-intentioned demands. Physicians in Virginia who have been working with the POST process are now connecting some very important dots. They are seeing the link between appropriately-timed, skillful advance care planning discussions and delivering compassionate care that is in line with patients' wishes. These physicians are asking the Virginia POST Collaborative to help them create a normalcy around advance care planning, a normalcy that communicates that "in our practice (or in our setting), we don't wait for a crisis to talk to you and/or your medical decision-makers about goals of care. We are offering a communication tool that others will recognize and honor, even when you can no longer speak for yourself."

POST can help free individuals who are frail or near the end of their lives and their loved ones to live life as fully as possible until the final celebration of life.

Study Questions

1. What went wrong in Mr. Jan's situation? Can you think of examples from your own life or practice where people did not receive the end-of-life care they said they wanted to receive? What contributed to this incongruency?
2. If you are a health care provider, what barriers exist in your system which impede your honoring the freedom of persons with advanced illness or frailty to have or to limit treatment across settings of care? Which are the most critical barriers to address first?
3. What are the key features of and benefits from a POST/POLST form?

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Resources

www.polst.org
www.virginiapost.org

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