

White Paper

The POLST paradigm and form: Facts and analysis

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This white paper, prepared by a working group of the Catholic Medical Association, provides a commentary on a new type of end-of-life document called a POLST form (Physician Orders for Life-Sustaining Treatment) as well as on its model (or "paradigm") for implementation across the United States. After an introductory section reviewing the origin, goals, and standard defenses of the POLST paradigm and form, the paper offers a critical analysis of POLST, including an analysis of the risks that POLST poses to sound clinical and ethical decision-making. The paper ends with several recommendations to help Catholic healthcare professionals and institutions better address the challenges of end-of-life care with alternatives to POLST.

Keywords: POLST, End of life care, Living will, Advance directive, Advance decision-making, In-the-moment-of-need medical decision-making, Euthanasia, Catholic health care

INTRODUCTION

The Challenge of Ethical Decision-Making at the End of Life

An attitudinal shift has taken place in the past half-century in the culture of end-of-life (EOL) care. The ancient and ineradicable fear of death has begun to live uncomfortably along side a waxing fear of living too long, of being a burden to one's caregivers and of languishing meaninglessly in debility, dementia, or terminal demise. Many factors account for this shift, but three seem most significant. First, the development of medical technologies and better health measures since World War II have meant that elderly people are living longer, which means more are living into a period of dementia frequently spending their final years in institutions away from their families and loved ones. Second, the loss of Christian faith has meant that people's thoughts on suffering, old age, and dying are decreasingly characterized by a sense of divine judgment (i.e. of a hope for heaven and desire to avoid hell), of the Christian meaning of suffering, and of the intrinsic value of human life. Finally, the weakening of our bonds of community has meant that more elderly experience loneliness and alienation when the measurable utility of their daily activities naturally decreases. One prominent American bioethicist writes: "many of us now worry that death will come too late—long after life has lost its usefulness and its savor, long after we have ceased to have a 'life,' perhaps long after we are even ourselves" (Hardwig 2009, 38). Consequently, more and more people are feeling an urgent need to control the conditions surrounding their own deaths in order to avoid what they believe may be "a death that comes too slowly and too late" (Hardwig 2009, 38).

This attitudinal shift has found expression in our practices of EOL care, in particular, the widespread use of EOL documents (such as living wills) directing the limitation of life-sustaining medical procedures. Although decisions limiting medical interventions can be legitimate and have been defended under certain circumstances in the Catholic tradition and in papal teaching since Pope Pius XII,¹ a disturbing mentality is gaining prominence in US health care. It advances the idea that disability and dysfunction can reduce the value of a person's life; it increases in vulnerable people a fear of living too long, of being a burden, and of dying—as its mantra goes—"without dignity"; and it promotes EOL documents as a means precisely for controlling the circumstances and timing of death.

Intent of This White Paper

This white paper considers in detail one potentially problematic response to this attitudinal shift in the form of a new type of EOL document known as Physician Orders for Life Sustaining Treatment (POLST)² and an organized campaign to encourage its widespread use. We acknowledge that the POLST form was developed to deal with real challenges in communicating and respecting patients' decisions regarding treatment at the end of life. We are well aware of the problem of over-aggressive medical care being delivered to patients who did not want it and whose conditions did not warrant it. Overtreatment at the EOL has resulted from at least three factors: (1) a medical culture characterized by paternalism that placed more value on the way physicians viewed death and dying than patients; (2) fear and uncertainty among patients and family members when dealing with their own or a loved one's demise; and (3) obstacles to learning,

documenting, and respecting patient wishes for their EOL care.³ However, medical paternalism has been replaced by a culture of autonomy that values patient wishes in medical decision-making sometimes to a fault. Fear and uncertainty at life's end cannot so much be avoided as its effects on decision-making minimized. Overcoming the range of obstacles to communication and implementation of patient wishes has been a primary objective of those promoting the POLST form, and of many other people as well. Like advocates of POLST, we are committed to overcoming obstacles to the clear communication of the values and wishes of patients. As Catholic physicians and healthcare professionals, we are also committed to upholding the values of Catholic health care, which include providing appropriate, ordinary treatments without discrimination and always providing the most basic forms of care that all patients need and deserve.

In contrast to advocates of POLST, however, we believe that the use of POLST forms will create unacceptable risks from both the perspective of good medical decision-making and good ethical decision-making. Although we recognize that POLST might offer some benefits to some patients, the benefits will be grossly outweighed by the harms and abuses that will result from use of the POLST form and the campaign to promote it.

We begin with a brief introduction to the POLST paradigm and form, and review arguments which favor its widespread use. We then outline the challenges that we believe POLST poses to good clinical care and ethical decision-making. We end with recommendations regarding POLST and propose some alternatives to the longstanding focus on advance decision-making models, alternatives that we think are more consistent with good clinical practice and Catholic moral principles.

REVIEW OF THE POLST PARADIGM AND FORM

Introduction to the POLST Paradigm and Form

Origin, Promotion and Spread⁴

The “POLST Paradigm Initiative” was created in 1991 by a task force of health-care professionals and ethicists from the Center for Ethics in Health Care at Oregon Health & Science University (OHSU)⁵ with the stated goal of facilitating patients' choices regarding end-of-life care, in general, and life-sustaining medical treatments, in particular. The “paradigm” was designed around a process of EOL counseling that would culminate in the completion of a “POLST form.”

Although the POLST form is examined in more detail below, it is distinctive in that, after being signed by a clinician, the form is immediately invested with the status of an actionable medical order, without regard to patient decisional capacity.

In 1991, the OHSU task force developed the approach and form that eventually would come to be known as POLST.⁶ A pilot instrument, called the “Medical Treatment Coversheet” (MTC), along with a process for implementation and evaluation, was created.⁷ For the first time, medical directives formerly dispersed over multiple forms were consolidated onto a single document.⁸ In 1993, the MTC's name was changed to “Physician Orders for Life-Sustaining Treatment (POLST)”⁹ and, in 1995, a POLST document was released for use in the state of Oregon. After that, the POLST paradigm and form began to spread across the United States. While a high degree of unity prevailed, given the origin of the POLST paradigm and materials at OHSU's Center for Ethics in Health Care,¹⁰ some states began to use other acronyms, including: POST (“Physician

Orders for Scope of Treatment”) in West Virginia; MOLST (“Medical Orders for Life-Sustaining Treatment”) in Maryland; MOST (“Medical Orders for Scope of Treatment”) in Colorado; and COLST (“Clinical Orders for Life-Sustaining Treatment”) in Vermont.

In 2004, OHSU’s Center for Ethics in Health Care assembled a task force of representatives from participating states to further facilitate the spread of the POLST paradigm nationally. The new National POLST Paradigm Task Force (NPPTF) established standards by which individual states could develop “endorsed” POLST programs (Sabatino and Karp 2011, 3).

States or regions interested in seeking endorsement from the NPPTF must submit an application that demonstrates that they meet the program requirements. The NPPTF supplies well-developed guidelines for implementing a statewide or regional POLST paradigm program including advice on assembling local task forces,¹¹ conducting pilot programs, identifying a core group of “physician champions” who will take leadership in program implementation and education,¹² addressing legal issues, training non-physicians to act as advance care planning facilitators,¹³ disseminating the program elements throughout the region, dealing with media, and conducting self-reviews.

All endorsed programs must meet a set of requirements that include the following:¹⁴

- (1) state or regional healthcare facilities and workers must recognize properly completed forms as current or (in some states, standing) medical orders;
- (2) training programs for POLST implementation must be instituted;
- (3) forms should be recommended for persons who might die in the next year, who suffer from “chronic progressive illness and/or frailty,” or who

are elderly “with strong, specific informed preferences” about their EOL options;

- (4) the signatures of patients or their surrogates on POLST forms are “strongly” recommended, but often not required, as “evidence that patients or their legal representatives agree with the orders on the form”;¹⁵
- (5) POLST forms should be the preferred advance-planning document in diverse health care settings (“e.g., emergency medical services, long-term care, and hospice”); their completion should be left voluntary; shared decision-making and patient wishes should govern their completion;
- (6) a plan should be developed for POLST implementation and ongoing evaluation;
- (7) “a single strong entity” should be identified who is willing to “accept ownership for the program” and is capable of implementing it.¹⁶

Efforts at spreading the POLST paradigm since 2004 have been remarkably effective. As of September 2012, fifteen states had programs “endorsed” by the NPPTF¹⁷ and 30 additional states (or state regions) had “developing” programs.¹⁸ Compare this with the 12 states programs and 21 developing programs in June 2011 (Saunders 2011, iv). POLST advocates are well-funded and organized, using an “incremental strategy” to get the program up and running throughout states (Saunders 2011, vi). Their commitment to POLST leads them to focus upon and accentuate its benefits. No state yet mandates the completion of a POLST form, but two states (Tennessee and Utah) require that the forms be offered to certain patients and residents (Sabatino and Karp 2011, v.).

In closing this brief historical review, we acknowledge that the POLST paradigm and form must be evaluated mainly in

terms of their nature and results, rather than in terms of the people and organizations associated with them. Still, it is worthy of note that POLST promotion was not a grassroots effort. Four foundations provided substantial donations for creating and promoting POLST—the Greenwall Foundation (Lewis-Husk and Garland 1999, 10), the Nathan Cummings Foundation, the Open Society Institute, and the Robert Wood Johnson Foundation.¹⁹ These same foundations also have provided significant funding for right-to-die organizations. To give only a few examples: the Greenwall Foundation funded Nancy Dubler, member of the Board of Advisors for Compassion & Choices, in 1991,²⁰ appointed Christine Cassel, physician-assisted suicide advocate as chair of its board of directors in 1999, and awarded a total of \$400,000 in grants to Choice in Dying a New York-based right-to-die organization, in 1994–1995.²¹ The Nathan Cummings Foundation awarded \$185,000 to Choice in Dying between 1996–1999.²² A decade later, Cummings continued right-to-die funding by awarding Community Catalyst \$135,000 to spearhead a MergerWatch campaign to “fight religious restrictions on end-of-life care.”²³ The Open Society Institute granted assisted-suicide advocacy group Compassion in Dying \$100,000 per year from 2000 through 2004.²⁴ Finally, the Robert Wood Johnson Foundation (RWJF) funded Choice in Dying at least as far back as 1998 with a grant for \$231,920.²⁵ Perhaps, then, it is not coincidental that POLST programs are strongly supported right-to-die coalitions²⁶ and some palliative care organizations.

Further, many hospitals, health systems have expressed support for POLST and promoted its use, up to and including the provision of payment incentives for physicians for completion of advance directive forms.

Goals and Rationale

POLST supporters believe the paradigm represents a necessary advance over older statutory models for advance care planning. Older models offered instruments to patients to express their wishes for EOL treatment, and immunity to doctors from homicide laws if they executed patients’ designated wishes in good faith. The “living will” was the first document of this kind to receive statutory support. Its originators conceived it as a means for legally specifying the conditions for dying—for revoking consent to treat—for patients with severe and irreversible pathologies.²⁷ California passed the first living will statute in 1976 (Sabatino 2010). Over the next 10 years the majority of states passed statutes establishing living wills as legally binding documents. In 1990 the U.S. Congress passed the Federal Patient Self-Determination Act²⁸ requiring health-care facilities to provide written information to patients concerning advance healthcare directives upon admission to the facility.

Advocates for patient autonomy began to argue that living will statutes were insufficient to ensure that patient care reflects patient preferences, especially in cases of advanced stage illness when critical decisions need to be made. Despite the widespread availability of living wills, the documents, they argued, were frequently unavailable when needed, lacked “clinical specificity with respect to the here-and-now medical decisions faced by seriously ill patients” (Sabatino and Karp 2011, 2–3), and did not embody the clinical normativity of a doctor’s order (Hickmen *et al.* 2005). These complaints were picked up by the 1990 task force at OHSU which argued that nothing less than translating patient preferences into actionable medical orders would overcome the problem.

The three aims of the POLST paradigm have recently been summarized (Sabatino 2010, 229):

- The first is advance care planning; the model requires a discussion on care options between POLST representatives and patients or their surrogates.
- The second is integrating patient preferences into physicians' orders by recording them onto POLST forms; each state adopts its own version of the form, but all forms share certain identical characteristics.
- The third is ensuring that the document "travels" with patients and remains applicable across all care settings.

The POLST form

State of Oregon POLST Form

See figure 1.

State of West Virginia POLST Form

See figure 2.

POLST forms, on which patients or their surrogates specify patient wishes regarding specific types of life-sustaining treatments, are the centerpiece of the POLST paradigm. POLST forms are usually printed on brightly colored paper (florescent pink, green, or yellow) so that they will stand out for ready reference in the patient's medical chart. The forms are similar to some advance directives (ADs) insofar as they employ a check-box format to make preferences known. But the POLST has one very important difference: traditional ADs provide discretion for clinicians to withhold or withdraw some or all life-sustaining treatments provided certain conditions regarding patient competency and health status (e.g., patient has been diagnosed with a terminal condition or a state of unconsciousness from which recovery is judged unlikely) are met in the future. A completed POLST form contains a clinician's signature investing it immediately with the status of an actionable medical order, whether or not the

patient lacks decisional capacity.²⁹ And, as a standing doctor's order, the form remains active across healthcare venues, whether a patient is in the hospital, at home, or admitted to a nursing home. It binds not only hospital and nursing home personnel but also emergency medical workers.

POLST forms always include three sections of information: introductory top section, specific medical directives, and bottom section containing the signatures of a healthcare provider (MD, NP, or PA is generally required) and/or a witness or witnesses.

Top section

The document's name and its acronym appear at the top of the page ("POLST" or MOLST, MOST, etc.) along with patient information and brief instructions directing medical practitioners to "follow these orders."

Medical directives

Three or four large boxes, depending on the form, contain specific medical directives. If patients have no pulse *and* are not breathing, the form directs caregivers to follow instructions in box one; if they have a pulse *or* are breathing, they proceed to boxes two to four. The wording of the following sections may vary slightly on different state forms.

The first directive is titled "Cardiopulmonary Resuscitation (CPR)." Patients or "facilitators" (term explained below) are directed to check one of two directives: "Attempt Resuscitation/CPR" or "Do Not Attempt Resuscitation/DNR."

The second directive is titled "Medical Interventions." One of three directives is checked: "Comfort Measures Only," "Limited Additional Interventions" (additional, that is, to comfort measures), including antibiotics and intravenous (IV) fluids; but it specifically directs practitioners not to use intubation, advanced

HIPAA PERMITS DISCLOSURE TO HEALTH CARE PROFESSIONALS & ELECTRONIC REGISTRY AS NECESSARY FOR TREATMENT			
Physician Orders for Life-Sustaining Treatment (POLST)			
<p>Follow these orders until orders change. These medical orders are based on the patient's current medical condition and preferences. Any section not completed does not invalidate the form and implies full treatment for that section. With significant change of condition new orders may need to be written.</p> <p>Guidance for Health Care Professionals. http://www.ohsu.edu/polst/programs/documents/Guidebook.pdf.</p>	Patient Last Name:	Patient First Name	Middle Init.
	Date of Birth: (mm/dd/yyyy)	Gender: <input type="checkbox"/> M <input type="checkbox"/> F	Last 4 SSN: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
Address: (street / city / state / zip)			
A Check One	CARDIOPULMONARY RESUSCITATION (CPR): <i>Patient has no pulse and is not breathing.</i> <input type="checkbox"/> Attempt Resuscitation/CPR <input type="checkbox"/> Do Not Attempt Resuscitation/DNR When not in cardiopulmonary arrest, follow orders in B and C.		
B Check One	MEDICAL INTERVENTIONS: <i>If patient has pulse and/or is breathing.</i> <input type="checkbox"/> Comfort Measures Only (Allow Natural Death). Relieve pain and suffering through the use of any medication by any route, positioning, wound care and other measures. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. <i>Patient prefers no transfer to hospital for life-sustaining treatments. Transfer if comfort needs cannot be met in current location.</i> Treatment Plan: Maximize comfort through symptom management. <input type="checkbox"/> Limited Additional Interventions In addition to care described in Comfort Measures Only, use medical treatment, antibiotics, IV fluids and cardiac monitor as indicated. No intubation, advanced airway interventions, or mechanical ventilation. May consider less invasive airway support (e.g. CPAP, BiPAP). <i>Transfer to hospital if indicated. Generally avoid the intensive care unit.</i> Treatment Plan: Provide basic medical treatments. <input type="checkbox"/> Full Treatment In addition to care described in Comfort Measures Only and Limited Additional Interventions, use intubation, advanced airway interventions, and mechanical ventilation as indicated. <i>Transfer to hospital and/or intensive care unit if indicated.</i> Treatment Plan: Full treatment including life support measures in the intensive care unit. Additional Orders: _____		
C Check One	ARTIFICIALLY ADMINISTERED NUTRITION: <i>Offer food by mouth if feasible.</i> <input type="checkbox"/> No artificial nutrition by tube. <input type="checkbox"/> Defined trial period of artificial nutrition by tube. <input type="checkbox"/> Long-term artificial nutrition by tube. Additional Orders: _____		
D	DOCUMENTATION OF DISCUSSION: <input type="checkbox"/> Patient (Patient has capacity) <input type="checkbox"/> Health Care Representative or legally recognized surrogate <input type="checkbox"/> Parent of minor <input type="checkbox"/> Surrogate for patient with developmental disabilities or significant mental health condition (Note: Special requirements for completion. See reverse side.) <input type="checkbox"/> Court-Appointed Guardian <input type="checkbox"/> Other: _____ Signature of Patient or Surrogate Signature: <i>recommended</i> Name (print): Relationship (write "self" if patient): This form will be sent to the POLST Registry unless the patient wishes to opt out, if so check opt out box <input type="checkbox"/>		
E	SIGNATURE OF PHYSICIAN / NP / PA My signature below indicates to the best of my knowledge that these orders are consistent with the patient's current medical condition and preferences. Print Signing Physician / NP / PA Name: <i>required</i> Signer Phone Number: Signer License Number: (optional) Physician / NP / PA Signature: <i>required</i> Date: <i>required</i> Office Use Only		
SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED. SUBMIT COPY TO REGISTRY © CENTER FOR ETHICS IN HEALTH CARE, Oregon Health & Science University, 3181 Sam Jackson Park Rd, UHN-86, Portland, OR 97239-3098 (503) 494-3966			

Figure 1. State of Oregon POLST Form.

airway interventions, or mechanical ventilation; or “Full Treatment.”

The third directive is titled: “Artificially Administered Nutrition,” directing one of three options: “No artificial nutrition by tube,” “Trial period of artificial nutrition

by tube” (space is provided for further handwritten instructions), or “Long-term artificial nutrition by tube.”

Some state forms contain a fourth box specifically related to the administration of antibiotics (otherwise antibiotics are

FORM SHALL ACCOMPANY PATIENT/RESIDENT WHEN TRANSFERRED OR DISCHARGED			
Physician Orders for Scope of Treatment (POST)		Last Name/First/Middle Initial	
		Address	
This is a Physician Order Sheet based on the person's medical condition and wishes. Any section not completed indicates full treatment for that section. When need occurs, first follow these orders, then contact physician.		City/State/Zip	
		Date of Birth (mm/dd/yyyy)	Last 4 SSN <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
		Gender <input type="checkbox"/> M <input type="checkbox"/> F	
Section A Check One Box Only	CARDIOPULMONARY RESUSCITATION (CPR): Person has no pulse and is not breathing. <input type="checkbox"/> Resuscitate (CPR) <input type="checkbox"/> Do Not Attempt Resuscitation (DNR/no CPR)		
When not in cardiopulmonary arrest, follow orders in B, C, and D.			
Section B Check One Box Only	MEDICAL INTERVENTIONS: Person has pulse and/or is breathing. <input type="checkbox"/> Comfort Measures Treat with dignity and respect. Keep clean, warm, and dry. Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. Do not transfer to hospital for life-sustaining treatment. Transfer only if comfort needs cannot be met in current location.		
<input type="checkbox"/> Limited Additional Interventions Includes care described above. Use medical treatment, IV fluids and cardiac monitoring as indicated. Do not use intubation, advanced airway interventions, or mechanical ventilation. Transfer to hospital if indicated. Avoid intensive care.			
<input type="checkbox"/> Full Treatment Includes care above. Use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated. Transfer to hospital if indicated. Include intensive care.			
Other Instructions: _____			
Section C Check One Box Only	ANTIBIOTICS <input type="checkbox"/> No Antibiotics <input type="checkbox"/> Antibiotics Other Instructions: _____		
Section D Check One Box Only in Each Column	Medically Administered Fluids and Nutrition: Oral fluids and nutrition must be offered if medically feasible.		
<input type="checkbox"/> No IV fluids (provide other measures to assure comfort)		<input type="checkbox"/> No feeding tube	
<input type="checkbox"/> IV fluids for a defined trial period		<input type="checkbox"/> Feeding tube for a defined trial period	
<input type="checkbox"/> IV fluids long-term if indicated		<input type="checkbox"/> Feeding tube long-term	
Other Instructions: _____			
Section E	Discussed with: <input type="checkbox"/> Patient/Resident <input type="checkbox"/> MPOA representative <input type="checkbox"/> Court-appointed guardian <input type="checkbox"/> Health care surrogate <input type="checkbox"/> Spouse <input type="checkbox"/> Parent of Minor <input type="checkbox"/> Other: _____ (Specify)	The Basis for These Orders Is: (Must be completed) <input type="checkbox"/> Patient's preferences <input type="checkbox"/> Patient's best interest (patient's preferences unknown) <input type="checkbox"/> (Other) _____	
Physician Name (Print)		Physician Phone Number	Office Use Only
Physician Signature (Mandatory)		Date	
FORM SHALL ACCOMPANY PATIENT/RESIDENT WHEN TRANSFERRED OR DISCHARGED			

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2010

Figure 2. State of West Virginia POST Form.

included under the “Medical Interventions” section); one of three directives can be checked: “no antibiotics: use other measures to relieve symptoms”; “determine use or limitation of antibiotics when infection occurs, with comfort as goal”; or “use antibiotics if life can be prolonged.”

Bottom section

At the bottom is a place to specify with whom the document's contents were discussed: patient, legal guardian, health-care representative, spouse, etc. Two signature lines then follow, one for a physician, nurse practitioner, or physician's assistant, which

is always mandatory, and one for the patient or legal guardian, which in some states is required (Washington) and in others only recommended (Oregon). Most state forms include a second page which records additional contact information of patient, caregivers, and practitioners.

Use of “Facilitators”

POLST advocates insist that the preeminent aim of the paradigm is to honor the informed wishes of patients. This requires that patients effectively be informed of their prognosis, their options for care, and the benefits and burdens of adopting one option over another, and that the information is translated into a plan of action consistent with patients’ value systems and desires.

The POLST paradigm proposes that non-physician healthcare personnel (e.g. nurses, social workers, chaplains, admissions coordinators, nursing home administrators) initiate advance care planning discussions with patients or their surrogates. These “facilitators,” as they are called, act as frontline implementers of the POLST paradigm (Sabatino and Karp 2011, 24). Completed forms are then referred to clinicians for signature.

The Respecting Choices program³⁰ run by Gunderson Lutheran Medical Center in La Crosse, Wisconsin, has become a national center for the training of POLST facilitators.³¹ Gunderson has operated regionally since the early 1990s promoting the use of advance care planning documents.³² Non-physician candidates must complete an approved training curriculum so they can serve as certified POLST facilitators.³³

Defenses of POLST

Since its origin in the 1990s, a variety of justifications have been put forth for

encouraging the use of POLST forms locally, regionally, and nationally. We briefly describe here some of these—without regard to order of importance.

Promoters of POLST argue that the form:

(1) *Ensures patient autonomy*: This has been an essential aim from the outset.

(2) *Standardizes documentation*: An early paper written by one of the architects of the POLST paradigm, Dr. Patrick Dunn, notes that the goal of the MTC was to standardize documentation (Dunn et al. 1996). His group felt the results of their research were so positive that (even prior to the paper’s publication) the group planned statewide implementation of the form. This was in 1995. Today, POLST promoters boast that POLST has become the “medical standard of care” in Oregon (used by all hospices and over 95 percent of nursing homes). Now many other states also seeking the goal of standardization have adopted the POLST paradigm.

(3) *Optimizes communication (to diminish anxiety and disputes among family members)*: A recent column in the *Wall Street Journal* emphasized the importance that patient wishes be shared both verbally and in writing with family members (Landro 2011). The author, Laura Landro, notes: “Making end-of-life decisions when a loved one’s wishes are not known can be difficult for families.” She narrates a case in which the competing concerns of the children of a terminally ill woman were quelled when they found out their mother had signed a POLST form limiting life-sustaining procedures: “the POLST made it easier for us because my mom had made her own healthcare decisions.”

(4) *Minimizes the use of unwanted interventions*: Some express fear or frustration regarding what they deem to be an excessive use of medical interventions at the end of life. This was graphically illustrated by an elderly British woman, Joy

Tompkins, who tattooed the acronym, “D.N.R.” (do not resuscitate) on her chest.³⁴ Proponents of POLST strongly believe that use of the document can limit unwanted interventions.³⁵

(5) *Simplifies decision making*: A single form is simpler than longer documents; consequently, POLST is seen to be a solution to the complexity of EOL decision-making.

(6) *Consistency of care across healthcare settings*: POLST advocates note the distinction between POLST and other types of ADs. POLST is valid across all health-care settings (Dominique 2009). This includes pre-hospital care by Emergency Medical Technicians, residential care facilities, and hospitals as well as between hospitals. In many cases, the forms are even honored across state lines.

(7) *Decreases interventions and the cost of care at the end of life*: Medical care at the end of life consumes 10–12 percent of the total healthcare budget, and 10 percent of the Medicare budget is spent during the last 30 days of life (Kurent 2000). POLST advocates cite statistics regarding POLST’s effectiveness for limiting interventions: “What we found was that if people marked ‘comfort measures only’ and ‘do not resuscitate’ and did not want to go back to the hospital, there was a 67 percent reduction in life-sustaining treatments, primarily hospitalization and emergency room visits.”³⁶ Gundersen Lutheran Health System in recommending legal recognition of statewide POLST systems claims its innovative advance directives program saves \$3,000 to \$6,000 per patient at the end of life.³⁷ John Gorman of the Gorman Health Group believes the “POLST solution” is an ideal way to cut costs: “There can be no hope of long-term Medicare solvency without more rational policy and assistance to seniors as they decide how they want to die—not when Medicare spends 1 in 4

dollars today on care in the last 6 months of life. The POLST solution ... is cheap, effective, and should be encouraged by CMS and the Administration.”³⁸

Problems with POLST

POLST, Patient Autonomy, and Good Moral Decision-Making

Perhaps nowhere in the area of health care has the intersection of human freedom and dignity been analyzed so extensively in Catholic teaching as in the development and application of the principles of “extraordinary” and “ordinary” treatment at the end of life and particularly in regard to the proper use of medically assisted nutrition and hydration. The following principles have been consistently taught the past 50 years:

- Patients have the right and duty to make decisions regarding the extent of the measures they choose to conserve their lives. They are not obligated to accept or pursue treatments that are “extraordinary” or “disproportionate.” In this regard, there is a wide scope for human freedom and for individual/subjective factors in someone coming to a conscientious judgment about limiting medical interventions at the end of life.
- At the same time, their choices are not ethical simply in virtue of the fact that patients are competent and legally authorized to make them. Patients are obligated to respect their own lives, and to conserve them by pursuing those medical treatments that are “ordinary” or “proportionate,” as well as to accept the most basic forms of human care. The same is true for surrogates making decisions on behalf of patients who are not competent to make their own decisions. In this regard, the teaching of the Church on the use of medically assisted nutrition and hydration

illustrates that there are foundational goods in human embodiment that must be respected in the free choices of patients and surrogates alike.

How should claims about the acceptability of POLST be evaluated in light of these principles? Although POLST is said to be designed for use by terminally and chronically ill elderly, there is nothing in most POLST programs or state POLST laws that actually limits it to this population. The POLST model introduces a paradigm shift into the statutory and procedural understanding of who is entitled to direct the refusal of life-sustaining treatments. The state laws that introduced living wills into common use in the 1980s limited the rightful use and execution of refusal orders to patients who, according to the judgment of two physicians, suffered from a “terminal condition” or were in a state of permanent unconsciousness. The pedagogical message of those laws was clear: the refusal of life-sustaining treatments is sanctioned for persons suffering from irreversible and terminal conditions; refusal was legally contextualized within and on behalf of the population of the dying.

The POLST model legislation *annuls the requirement that a patient must be terminally ill* before he or she may direct the withholding or withdrawal of life-sustaining treatments.³⁹ We believe that it is naïve to think that if the law makes provision for the inappropriate use of refusal orders by populations who are not terminally ill, that some people will not take advantage of those provisions.

Moreover, as noted, Catholic teaching distinguishes between rightful and wrongful refusal decisions by using the terms “ordinary” (proportionate) and “extraordinary” (disproportionate) means of medical care. We have an obligation to accept ordinary/proportionate means of medical

treatment, and may forgo extraordinary/disproportionate means. The POLST model and POLST forms make no distinction between ordinary and extraordinary means. This sets up an obvious conflict between the moral obligation of Catholic institutions *not* to honor (in the words of ERD, no. 24) “an advance directive that is contrary to Catholic teaching,” and the legal liberties of patients in those institutions to write such a directive.

Finally, every POLST form has a section dedicated to the refusal of nutrition and hydration. But Pope John Paul II in 2004 clarified that the administration of nutrition and hydration, even by artificial means, “should be considered, in principle, *ordinary* and *proportionate*, and as such morally obligatory, insofar as and until it is seen to have attained its proper finality.”⁴⁰ In all but cases where a patient is imminently dying or rare instances where food and water are no longer adequate to sustain bodily life or their administration causes excessive suffering, the decision to forgo them would be wrongful. But because the POLST functions as an actionable medical order, directives to withhold food and water, as well as other orders to withhold morally “proportionate care,” may be seen as legally binding and thus influence Catholic healthcare institutions and providers who feel compelled to obey.

POLST and Good Clinical Care

EOL decisions are among the most important medical decisions people can make. Therefore they should be made in light of the concrete facts of a patient’s medical situation, in consultation with skilled medical practitioners, and with due respect for the goals and desires of the patient. The POLST design makes this difficult to carry out for at least five reasons.

First, the POLST form offers a simple check box list of treatment options. Complex medical decisions are reduced to over simplified scenarios that do not reflect the nuances of actual medical practice. For example, Section A offers a choice between providing or withholding CPR—specifically, when a patient has no pulse *and* is not breathing. The patient must pre-determine either to consent to attempted resuscitation or to reject it. But what if a patient presents with no palpable pulse but is breathing or has a pulse but is not breathing, for example, as in a choking victim? A simple Heimlich maneuver might be all that is needed in this case.⁴¹ The healthcare provider is not allowed to use his clinical judgment to assist the patient, but must proceed to Section B and C. Once there, the provider is limited to the vague courses of pre-selected options that are listed there. But every patient and clinical presentation is unique and personal. Proper patient care requires the aptitude and readiness to respond to situations that are complex and varied. It cannot (and should not) be reduced to a simple predetermined checklist. Each medical decision needs to be made in the context of a patient's presenting situation, which includes his psychosocial situation especially in regard to his family members.

Second, patients may make their choices weeks, months, or even years before those choices will be carried out. Ordering future medical decisions in this way has limitations and potentially serious outcomes.⁴² The decision to forgo antibiotic use could be a good clinical decision in one who is terminal and imminently dying. But it could also be a poor decision in an acute exacerbation of a chronic disability that may be readily responsive to a short course of antibiotics. The forms are completed prior to the time that many people know the exact nature of their

conditions or the range of reasonable treatment options.⁴³ In other important areas of life (e.g. investing), people are ill advised to make consequential decisions without knowing all the facts. But the POLST paradigm invites patients to make the most consequential decision of their lives before many facts are even possibly knowable: What precise ailment will I be suffering from? What treatment alternatives will be available? What probability of medical benefit does each offer? What burdens are associated with each? Will I have the opportunity to receive the last sacraments of the Church before I die? Will I have made my final peace with God and neighbor? Will my children or other loved ones be at my bedside or will I die alone? Will I have any measure of consciousness to put other affairs in order? How will my decision affect those around me? A POLST form is a blunt and inadequate instrument that is as likely to do damage as good for people at vulnerable moments of life.

Third, as noted above, depending on the State of origin, the POLST may not require a patient's signature. This sets up a unique medical-legal situation when specific DNR orders or termination of care orders are expected to be followed without a patient's signature. All other forms of advanced directives such as living wills and durable powers of attorney are signed by the patient and witnessed. Defenders of POLST reply to this criticism by noting that traditional medical orders, such as hospital DNRs, operate with only a clinician's signature.⁴⁴ If this is not problematic, why should there be a problem with POLST documents? This reply is unsatisfactory. Hospital DNR orders by a physician are inherently contextual, that is, they reflect the actual circumstances of a patient's overall condition at the time the order is made. POLST orders by a physician are not.

Fourth, the POLST design as a pre-signed medical order is transferable across care settings. This could allow a healthcare provider in one setting to order that EOL care be withheld from a patient who has been transferred to a different setting, without the provider having privileges within the patient's new medical facility. When a patient is transferred (admitted) to a new facility, standard medical practice is for the admitting physician at that facility to write new medical orders based on the patient's current medical condition. It seems that POLST abrogates this practice. Moreover, the transference may lie outside the scope of hospital bylaws, which generally require that ordering doctors must be on staff in the particular institution. The order is also effective immediately upon arrival in the facility's emergency room or hospital room without the standard procedure of assessing the patient's medical situation, consulting the patient or patient's surrogate and writing new appropriate orders. This may preclude reasonable clinical care based on the presentation of the patient. Again, in order to properly assess the medical situation in view of the patient's goals and desires, the medical decision-making process needs to be contextual.

Fifth, we have concerns with the verbiage used and the underlying psychology of the POLST form, which seem to carry a bias in favor of non-treatment. The Wisconsin POLST, for example, rather than using the term "full treatment" uses the term "aggressive treatment." Patients are asked to choose between "aggressive" measures, "limited" measures, or "comfort" measures. "Aggressive" measures are defined as "endotracheal intubation, advanced airway, and cardioversion/automatic defibrillation." The term "comfort" measures, however—which, of course, means non-treatment—is explained as follows: "The patient is treated with

dignity, respect and kept clean, warm and dry... offer(ed) food and fluids by mouth, and attention is paid to hygiene... measures are used to relieve pain and suffering," etc. The tone of presentation of the two options is quite different.⁴⁵ Similarly, the Washington State POLST, under the section dedicated to the administration of antibiotics, offers as the third of three options: "use antibiotics if life can be prolonged." The term "prolonged" has negative implications. A "prolonged absence" implies an unwelcomed delay; a "prolonged stay" implies overstaying one's welcome; a "prolonged period" implies dragging on and on. Why not use neutral language such as "use antibiotics if medically indicated for healing or preservation of life"? Additionally, most state forms use the term "artificially administered nutrition," rather than neutral terms such as "medically administered nutrition and fluids" or "provision of food and water."⁴⁶ Something "artificial" is opposed to what is "natural." The POLST gives the impression that patients who are fed and hydrated via technical means are being kept alive unnaturally.

POLST, the Role of Physicians and Fundamental Ethical Values

Role of the Physician

At the heart of medicine is the individual encounter between physicians and patients. Physicians must conscientiously do their best for patients including providing explanations about patient conditions, a prognosis and a set of treatment alternatives specifying the benefits and burdens of each alternative. Truly informed consent requires precise, truthful and clear information at the proper time in a manner that patients and their families can understand.

This need for clear communication is never more keenly felt than when

physicians care for dying or chronically ill patients who are incapable of understanding the gravity of their situation. Doctors influence not only with their words, but by their attitudes, the amount of time they spend with patients, the frequency of their visits, the personal feelings they express about certain types of disease, and even their own views on death. In 1806, Chrisoph Hufeland recognized this issue when he wrote: “It is not up to [the doctor] whether ... life is happy or unhappy, worthwhile or not, and should he incorporate these perspectives into his trade ... the doctor could well become the most dangerous person in the state” (Smith 1997, 70–1). He recognized that the tremendous power given to physicians by society can be used for good when patients are viewed as having inherently equal worth, but can be abused when doctors impose their own values.⁴⁷

Physician–Patient Relationship

That power for doing good is principally expressed in and through physicians’ diagnostic expertise and ability and readiness to offer precise and timely treatment of sickness. Because of the difficulty in predicting all possible contingent scenarios at the end of life, and because patients and families often change their minds at critical moments, the POLST may place unreasonable restrictions on their ability to know the real-time wishes of patients and to offer them the best care possible. As one author wrote: ADs “promise more control over future care than is possible” (Perkins 2007). Many primary care physicians practicing in large medical systems do not care for their own patients during emergency visits or hospital admissions—the times of greatest vulnerability of death. Deprived of the security of personal relationships with their physicians, patients may seek comfort through instruments

like POLST. Yet beyond the marks on the page, these documents are mute. They do not know their patients, express no expert opinions, are never poised and ready to meet the complex demands of the unexpected; in every situation, they mouth the same words. They cannot possibly embody the knowledge, readiness, and personalized care of a doctor who has known his or her patient for many years.

The problem of the weakening of the doctor–patient relationship is bigger than the POLST form. Because of a tight practice schedule and a large impersonal community, physicians may know little about their patients or their families. Clinic time is limited for detailed discussions about values, even when completing forms treating subjects as important as EOL wishes. The goal of an EOL planning meeting can easily change from having a thorough discussion of values, wishes, and options to merely completing the form. Talking about the end of life may be left to other staff and the physician is presented with a completed form to sign, or even at times the form is signed without any conversation with the patient at all. If physicians do not participate in the discussion in a meaningful way, or take any kind of detailed notes about subtleties of their patients’ wishes, how will they be able to provide the kind of care that patients think they have communicated? Does this constitute informed consent?

Marginalization of the role of physicians and delegation of the informed consent process to facilitators

Education and counseling about medical information necessary to informed consent belong to the physician–patient relationship. The American Medical Association (AMA) Code of Medical Ethics states: “The patient’s right of self-decision can be

effectively exercised only if the patient possesses enough information to enable an informed choice... The physician's obligation is to present the medical facts accurately... Informed consent is a basic policy in both ethics and law that physicians must honor."⁴⁸ The AMA also counsels physicians that "in the communications process, you, as the physician providing or performing the treatment and/or procedure (*not a delegated representative*), should disclose and discuss with your patient" the different treatment options available and the nature, purpose, risks and benefits of each option, and the risks and benefits of forgoing particular treatment options. "This communications process," it continues, "or a variation thereof, is both an ethical obligation and a legal requirement spelled out in statutes and case law in all 50 states."⁴⁹

As stated above, under the POLST paradigm, non-physician facilitators undertake this critical communications process: they approach patients, initiate POLST conversations, "assist in making informed end-of-life decisions,"⁵⁰ complete the POLST forms, and submit the forms to doctors for their signatures. Sabatino and Karp state that facilitators "provide much if not most of the patient counseling and assistance in completing POLST forms" (Sabatino and Karp 2011, 24). Although this may be an efficient way to increase the utilization of advance decision-making documents in a given community,⁵¹ it marginalizes the role of physicians from an area of medical care that by definition—"end-of-life"—has life and death implications. "More often than not the physician role is to verify the choices made and the process used and then sign off on the orders."⁵⁰ One study found that, whereas physicians are required to sign POLST forms, 72 percent of the POLST forms of nursing home residents were completed by facilitators; "in light of such data, physician

participation in POLST completion appears to be tepid" (CANHR Policy Brief 2010, 3).

Moreover, physicians bear primary responsibility for patients and, as such, write orders directing care and treatments for their patients. Other healthcare professionals, primarily nurses, are in frequent, direct contact with the patient and in that role are responsible for carrying out these orders. It is standard care for nurses to inform physicians of the status of their patients and of any unexpected developments or adverse reactions to treatments. This collaborative relationship, mutually informing, enhances patient safety and cohesiveness of the team. In light of this, it is concerning that the POLST forms from 10 states have printed at the top statements to the effect: *First Follow These Orders, Then Contact Physician* [original emphasis].⁵² Healthcare professionals have a responsibility to carry out doctors' orders, but never without question. Acting in accord with this statement could jeopardize the safety of patients. Licensed healthcare professionals are placing their professional conduct at risk by carrying out orders that may not be appropriate for the patient.

Facilitator scripts and materials contain negative bias regarding life-sustaining treatment

Facilitator trainees, as nonphysicians, have little or no preexisting knowledge regarding indications for and relative benefits and burdens of life sustaining treatments.

However, facilitator training scripts and materials have been found to have an inordinate emphasis on burdens of life sustaining treatments⁵³ while dismissing the disadvantages and potential complications of rejection of treatments.⁵⁴ For example, the likelihood of certain death without life-sustaining treatments seems to be absent from discussions. Having no prior

knowledge and in light of training that may be negatively biased, facilitators may take on negative attitudes toward life-sustaining treatments. In one study, for example, California Advocates for Nursing Home Reform found that materials accompanying POLST forms are “meant to sway patient decisions ... [and are] clearly intended to convince patients or their representatives to forego CPR” (CANHR Policy Brief 2010, 5).

Healthcare institutions, employed facilitators, and potential conflict of interest

Sabatino and Karp (2011, 13–16), as stated above, describe the central role played by facilitators in implementing the POLST model. Local healthcare organizations, hospitals and nursing homes, may send their non-physician staff (social workers, nurses, administrative staff) for facilitator training, engaging them in POLST form completion and submission to physicians. We question whether such organizations and institutions possess legitimate authority to delegate informed consent and thereby alter the physician–patient relationship. It appears that most facilitators are employees of the institutions in which they perform POLST patient facilitation. Thus, it seems reasonable to consider whether hospital-employed facilitators create a financial conflict of interest in their institution-appointed duties. Given that hospital Medicare reimbursement is a fixed price based on admission diagnosis (diagnosis-related group) (Reinhardt 2009), when patients agree to fewer life sustaining treatments upon conversations with negatively biased facilitators, hospital costs decrease while profits increase. This is not to imply that administrators seriously ponder financial trade-offs for their clients, even in light of the cost crisis in

health care. Nonetheless significant cost savings have been achieved at the end of life with POLST/facilitator programs and may constitute a powerful driver for subscription in facilitator programs.⁵⁵ We should not forget examples where medical plans have unethically balanced costs of treatment against patients’ lives, such as a disturbing case where the Oregon Health Plan refused to cover expensive chemotherapy for a woman with lung cancer, but offered to cover drugs if she wished to consider physician-assisted suicide.⁵⁶

Lack of Evidence that POLST Orders Reflect Patient Wishes

The POLST paradigm was designed “to ensure that seriously ill patients can choose the treatments they want and that their wishes are honored by medical providers.”⁵⁷ But whether POLST accurately captures the treatment preferences of persons for whom POLST orders are written is an important question. Discrepancies between patient wishes and the content of orders can be particularly serious, given the irreversibility of some orders.

Research summaries on the national POLST web site report that medical care is almost always consistent with POLST orders (i.e., that POLST orders are followed) and that such orders record a high percentage of treatment refusals.⁵⁸ In studies involving a group of 255 deceased patients, the Hammes study found that medical caregivers followed POLST orders over 90 percent of the time; and the orders refused full medical treatment 92 percent of the time.⁵⁹ But a high percentage of POLST compliance and treatment refusal are not in themselves evidence that POLST orders reflect patient wishes.

According to the national POLST web site’s Quality/Research tools, a 2004 study

by Meyers *et al.* (2004) is “the only published evaluation of whether POLST orders match patient preferences.”⁶⁰ But the authors of the Meyers study state that the small sample size and other limitations “preclude an accurate determination of the form’s effectiveness and diminish any inferences that can be made.” (Meyers *et al.* 2004, 43) Despite this, the national POLST web site references the Meyers study to say POLST accurately conveys wishes 90 percent of the time.⁶⁰ Moreover, a recent major study involving over 1700 nursing home residents, called for “additional data that the orders on the POLST form are reflective of resident treatment preferences, as has been suggested by previous pilot research [the Meyers study]” (Hickman *et al.* 2010, 1247).

Further, even if wishes were recorded accurately, there is evidence that the stability of recorded decisions is low. Researchers have found that patient preferences for life-sustaining treatments change up to 77 percent of the time when questions are asked differently (Fagerlin and Schneider 2004, 33), and patients are frequently uncertain when their wishes are initially recorded (up to 45 percent of the time) (Sudore *et al.* 2010).

Other research has examined how patient decisions vary depending on possible outcomes. A study in the *New England Journal of Medicine* (Fried *et al.* 2002) found the vast majority of patients who would qualify for a POLST in fact want treatment. They enrolled 226 people (with advanced cancer, congestive heart failure or chronic obstructive pulmonary disease) whose primary care physicians said had limited life expectancies. Asked if they wanted medical treatment to avoid death and return to their current state of health, 88.8 percent said yes to more than a month in the hospital, being on a ventilator, in the ICU, having surgery or the

like. Another 9.9 percent said yes to treatments such as a week in the hospital and IV antibiotics. The desire for treatment did not drop significantly until the odds of survival with recovery dropped below 10 percent.⁶¹ Just over half of them died during the following two years, yet their desires for intensive treatment with only a 50 percent chance of recovery stayed relatively stable: during the four 6-month periods over the two years, the desire for intensive therapy was 87, 90, 93, and 76 percent (Cosgriff *et al.* 2007). This disparity in patient preferences as compared with typical POLST orders (in a rather large sample and well designed research study) is disturbing (see table 1).

Table 1. *Percent of patients desiring treatment*

	POLST preferences (%)	Fried <i>et al.</i> (%)
Hospitalization	38	98.7
Intensive care unit	8	88.8
Mechanical ventilation	8	88.8
Intravenous antibiotics	43	98.7

Moreover, Fagerlin and Schneider (2004, 33) note that “...answers [on advance decision making documents] are shaped by the way questions are asked. Preferences about treatments are influenced by factors such as whether success rates or failure rates are used, the level of detail employed, and whether long- or short-term consequences are explained first.” They cite an example: “201 elderly subjects opted for the intervention 12% of the time when it was presented negatively, 18% of the time when it was phrased as in an advance directive already in use, and 30% of the time when it was phrased positively. Seventy-seven percent of the subjects changed their minds at least once when given the same case scenario but a different description of the intervention”

(Fagerlin and Schneider 2004, 33). They further observe that living-will type of documents “have come to have two purposes that are in tension... to honor patients’ autonomy by having them make their own decisions... [and] to prevent dying patients from being over treated. The second purpose has become so central in the mind of patients and the doctors, social workers, and lawyers who counsel them that the first purpose quite gets lost. But these are truly life-and-death decisions, and they deserve to be made with greater care than we fear they currently are or could be in a world where most of us have living wills.”⁶²

Hickman et al. (2010), found that nursing home residents with POLST forms are far more likely to have orders limiting life-sustaining treatments beyond “No CPR” than those with conventional advance directives (98.1% vs. 16.1%). In addition, fewer life-sustaining treatments, such as IV fluids, are utilized in comparison with patients having conventional advance directives. The authors conclude that: “The POLST program’s association with less use of unwanted life-sustaining treatments in a large, geographically disparate sample is unprecedented.”

The assertion that POLST lessens “unwanted life-sustaining treatments” must be challenged. In light of innovations of the POLST paradigm—facilitated informed consent, unwitnessed interviews, lack of patient signature—how can medical professionals called upon to execute POLST orders be confident that treatments are truly unwanted? We find troubling the lack of reliable research to confirm that POLST accurately captures the wishes of patients about life-sustaining treatments.

We also suspect that POLST may be fraught with a tendency for errors, given pressures to produce real-time POLST orders in locations where the form is

“required” for admission to hospitals and nursing homes (CANHR Policy Brief 2010, 6), and at sites that make patient/surrogate signature optional. Thus the inherent problems of advance decision-making may be amplified by the immediacy of POLST order preparation and implementation.

The President’s Council (2005, 76) states: “a living will that is so ‘effective’ in this sense might well be too effective, too easy to act on quickly, when the family might wish to make care decisions more deliberately, in light of changing circumstances and new information.” It should be noted that in some jurisdictions, POLST forms override all other advance directives, including the agent specified under a durable power of attorney.⁶³

POLST Candidacy: The Ever-Expanding Circle of Inclusion

POLST was originally conceived for patients clearly at the end of their lives, in controlled healthcare settings, for whom disabling life-threatening complications were anticipated (Briggs 2003). Such restrictive parameters for use of POLST can be replaced with looser limits or almost no limits, as borne out in various locations throughout the country.

For example, the first version of a POLST used at Gundersen Lutheran in LaCrosse, Wisconsin, was for patients with renal failure who could suffer a stroke or heart attack while on dialysis (Briggs 2003). As described below, POLST is now being recommended for people who may be expected to live for five more years or who simply live independently in low-income senior apartment complexes.

Deciding that a person was near the end of life was at first based on a life expectancy of six or fewer months if an illness runs its course.⁶⁴ Because estimating when someone will die is very

difficult, even for doctors who work with the dying, the following question was developed initially to encourage patient referrals for hospice services, “Would you be surprised if this patient died in the next 6 months or so?” (Lynn *et al.* 2008). The question for POLST eligibility is usually: “Would you be surprised if this patient died in the next year?”⁶⁵ Some systems use two years.⁶⁶ In Oregon, the question is “Would I be surprised if this patient died or lost decision-making capacity in the next 1–2 years?”⁶⁷ Legislation recently passed in New Jersey not only has expanded POLST to patients who have a life expectancy of less than *five* years, but also to patients who “otherwise wish to further define their preferences for health care, to make their preferences concerning life-sustaining treatment or other interventions known in advance.” Such a description could encompass any person in any state of health.

Other examples may be given. California Advocates for Nursing Home Reform (CANHR) reported that “some providers have been giving out POLSTs to practically all patients, healthy or ill, with healthcare directives or not.”⁶⁸ In one Wisconsin community all individuals in low-income senior apartment complexes are considered eligible for POLST.⁶⁹ Some recommend POLST for all nursing home residents,⁷⁰ even though over half of them live in nursing homes for more than a year (Jones *et al.* 2009, 4), and 25.3 percent for more than three years.⁷¹ People discharged from hospitals to their own homes with home care are another category (Jones *et al.* 2009, 4). In West Virginia, the form is to be “completed for any individual with a chronic illness who may need a life-sustaining treatment in the future to attempt to survive.”⁷² This criterion would include a 25-year-old with asthma or diabetes; for that matter most of us within some finite period of time

will have a chronic condition, and on any given day each of us could find ourselves in an emergency situation needing treatment to survive.

Yet another expansion is to individuals with disabilities and children. According to the Delaware MOLST Coalition, citing New York, “persons with mental retardation or developmental disabilities or persons with mental illness *with capacity* (capable of making their own decisions)” can complete MOLSTs as can parents of minor children.⁷³ In September 2012, the California’s Children’s Hospice & Palliative Care Coalition offered a seminar entitled “POLST: Beginning the Conversation for Pediatrics.”⁷⁴ This Coalition claims its “success is particularly vital to the more than 17,000 low-income families in California whose children have been diagnosed with life-threatening conditions such as cancer, cystic fibrosis, muscular dystrophy, and cerebral palsy.”⁷⁵

While POLST was originally designed for patients at the end of their lives and continues to be described as such,⁷⁶ nearness to end of life is by no means the exclusive criteria for POLST. Beginning with the question formulated above and extending over time and with new POLST rollouts, the paradigm develops an ever-broadening circle of inclusion. The expanding of “eligible” populations through loosened inclusion criteria is one more factor widening the doorway for misuse, for medically inappropriate restrictions of treatments leading to the untimely deaths of patients, especially those who are low-income. Recently, in Delaware, where POLST is called MOLST⁷⁷ the State Division of Public Health asked all health-care workers to refrain from following MOLST orders until new state regulations are issued because “there have been reports of facilities and healthcare providers completing ‘MOLST’ forms on patients who

have not been determined to be terminally ill.”⁷⁷

POLST Compliance and Respect for Conscience

A growing number of states currently have POLST programs and many others are developing them. In considering the impact that such programs have or may have on conscience rights or the religious freedom of healthcare providers, it is important to recognize that differences exist between state programs. To illustrate these variations we focus on POLST programs in three states, Maryland, New Jersey, and Oregon, asking the following three questions: Is POLST addressed in the law? Are healthcare providers compelled to execute and comply with POLST forms? What can be done to respect conscience and religious freedom?

POLST and the Law: Are NPPTF endorsed POLST programs always introduced through the state legislative process? States address POLST through various mechanisms, which may be laws, regulations, or guidelines. For example, in Maryland, the MOLST program is contained in the state code⁷⁸ with regulations in the process of being formulated by the Maryland Dept. of Health and Mental Hygiene. Likewise, New Jersey law addresses POLST.⁷⁹ However, Oregon, the state where POLST originated, has no legislation pertaining to POLST. It is only addressed in Oregon Administrative rules.⁸⁰

Freedom of conscience and religious liberty: Are healthcare providers compelled to execute and comply with POLST forms? Proponents often imply that once a program is implemented POLST forms are required, recognized, and binding. Yet, state requirements and exceptions vary.

In Maryland, pending regulations state that certain facilities will be *required* to accept, update, and complete a MOLST

for each patient during the admission process.⁸¹ This reflects the state law, which provides that a health facility *shall* accept a completed MOLST upon admission for *each* patient or complete a MOLST order during admission for *each* patient being admitted or discharged.⁸² Furthermore, the law says that a facility must comply with all medical orders in a MOLST form regardless of whether the physician or nurse practitioner who signed the form has admitting privileges or is otherwise credentialed at the facility.⁸³ However, there appears to be an exception to this requirement to comply since it refers to certain instances covered in another portion of the Maryland code addressing advance directives.⁸⁴ Yet, even this limited exception seems to tilt toward requiring compliance.

The administrative rules in Oregon state that physicians and physician assistants must comply with POLST, even if the physician, physician assistant, or nurse practitioner who executed the form does not have admitting privileges at the facility where the patient is being treated.⁸⁵ However, the rules do state that, in keeping with the state’s advance directive law, unwilling providers may refuse to comply.⁸⁶ This provision includes an exception for facilities, organizations, or providers based on religious or philosophical beliefs but does require that the provider must be willing to discharge or transfer the patient.⁸⁷

In New Jersey, POLST forms are intended to be honored by all personnel attending the patient.⁸⁸ However, private, religiously affiliated healthcare institutions are not required to participate in withholding or withdrawing of specified measures⁸⁹ if particular requirements are met. Those requirements include the formulation of institutional policies and practices which are properly communicated to the patient or the patient’s representative upon

admission or as soon thereafter as possible and, if conflicts between the healthcare provider and patient cannot be resolved, the provider takes all reasonable steps to transfer the patient.⁹⁰

Protecting conscience and religious liberty: What can be done to respect conscience and religious freedom? The above discussion refers to only three states but provides an illustration of ways in which healthcare provider compliance varies. In addition to laws, regulations, and guidelines that address noncompliance, it is likely that various programs and facilities may exert pressure on physicians to comply. Thus, it is important that facilities and providers take steps to preempt any appearance of coercion. We discuss some of these steps below.

Problems with Advance Decision-Making in General

Do advance planning documents facilitate good moral decisions?

Catholic moral principles and advance medical decision-making:

The *Ethical and Religious Directives* state:

In compliance with federal law,⁹¹ a Catholic healthcare institution will make available to patients information about their rights, under the laws of their state, to make an advance directive for their medical treatment. The institution, however, will not honor an advance directive that is contrary to Catholic teaching. If the advance directive conflicts with Catholic teaching, an explanation should be provided as to why the directive cannot be honored (No. 24).

This directive was added after Congress in 1990 passed the federal *Patient Self Determination Act* requiring healthcare facilities to make available to adult patients

upon admission to the facility information about advance healthcare directives. It should not be read as an endorsement by the U.S. bishops of advance directives or advance decision-making. It states that some decisions specified on advance planning documents may conflict with Catholic moral teaching; if they do, they should not be honored. In compliance with federal law, it is vital that patients should be informed of this policy by Catholic institutions upon admission.

How can patients and their physicians ensure that advance planning decisions are consistent with moral principles? And how do healthcare workers determine whether an advance directive conflicts with Catholic teaching?

ERDs 56 and 57 state that decisions to refuse life-sustaining treatments are legitimate as long as these treatments are disproportionate/extraordinary. But in what situations can a Catholic determine *in advance* that a life-sustaining treatment is disproportionate, removed from the context of the specific, future situation of medical need?

We would like to suggest a simple test to determine whether the risks of advance decisions to withhold specific treatments are justifiable, through the satisfaction of two separate but simultaneous conditions. (By advance decisions, we are talking about decisions made well before patients find themselves in a compromised state of health; on advance planning forms, such decisions are often preceded by phrases such as, “If I am in a condition such as terminal disease or dementia...”. However, POLST forms contain no such clarifying conditions).

The first condition we call “medical imminence,” and addresses the question, “Which decisions to withhold treatment must be made in advance?” To fulfill this condition, the treatment is of the type that must be administered immediately or a

patient will die. Why “medical imminence”? Because when considering non-imminent life-sustaining procedures (such as antibiotics or medically administered nutrition and hydration), there is *no urgent need* for advance decision-making, there is time to reasonably consider all options once the need arises. In short, decisions for or against non-imminent treatments are best made, together with patient and/or surrogate, at the time the need is apparent, weighing actual medical circumstances rather than a “best guess” of some future theoretical situation that has been posited.

The second condition we call “sufficient moral foresight.” It would only be justifiable to reject in advance some treatment that sustains life if a patient could accurately judge now that receiving that treatment in the future would be extraordinary or disproportionate. However, given the multiplicity of factors that might impact on such an analysis—factors that create the setting in which a treatment becomes proportionate or disproportionate, the ability to make *in advance* an accurate judgment in this regard is limited. There are exceptions—mechanical ventilation may meet both the condition of medical imminence and sufficient moral foresight, as, for example, when an individual is diagnosed with end-stage chronic obstructive pulmonary disease when eventual extubation is unlikely. There may be other examples, particularly as this relates to cardiopulmonary resuscitation (meaning chest compressions) in certain individuals with advance illness.

Deciding in advance to withhold life-sustaining treatments without such due consideration poses unacceptable and unjustifiable risks to the good of the patient. We believe that the paradigm of soliciting treatment choices in nursing homes using checkboxes on a form, far in advance of the actual medical events, may

pressure patients and surrogates to make inappropriate decisions lacking due moral consideration. We strongly recommend that this paradigm be abandoned.

RECOMMENDATIONS

To assist physicians and healthcare facilities in offering an effective response to the problems we have discussed, we offer the following recommendations.

Replace the POLST Model of End-of-life Care with “Preparation for in-the-Moment-of-Need Medical Decision-Making”

If the model of advance medical decision-making as formulated in POLST forms is ill advised, what model then should be used in its place? We recommend a model that Sudore and Fried (2010) referred to as “preparation for *in-the-moment-of-need medical decision making*.” Sound clinical and ethical decisions are best made when actual medical facts and the complexities of patients’ conditions, including previous responses to treatment and burdens and benefits of available options, are weighed and considered in the moment of medical need. This requires that doctors and other caregivers have the information necessary to make the appropriate decisions. Since relevant information, especially in crisis situations, cannot always be communicated orally by patients in their moment of need, we recommend that patients, especially elderly and chronically ill patients, should provide authorization in advance to surrogate decision makers, who know of their values and are willing to work with medical teams, to speak on their behalf in cases of incapacitation. Sudore and Fried recommend that surrogates engage in open discussions about

patients' values and be given leeway to work with doctors to make the best decision they can in light of these values. A physician should engage patients and surrogates in conversations ahead of time, and prepare them to be able to participate in making the best possible medical decisions in-the-moment. Compare this to the all or nothing approach of advance decisions where questions are often posed as, "If you suffer a serious complication, do you want everything done or stop all efforts?"⁹² Real life in-the-moment decisions can consider a variety of appropriate options centered on the patient's actual situation—weighing specific benefits and burdens of each—unlike the limited choices and considerations offered in advance on a POLST form.

Recommendations for Caring for "Unbefriended" Elderly Persons

- (1) *Raise awareness of the problem of the unbefriended:* Patients who lack decisional capacity, have no advance directive, and no one to serve as their healthcare surrogate are sometimes referred to as "unbefriended." They are at risk of overtreatment, undertreatment, or treatment inconsistent with their values.⁹³ Unbefriended people who become problematic discharges are estimated to account for 1–2% of patients.⁹⁴ The majority of unbefriended people are thought to live in hospitals and nursing homes. Roughly 3–4% of nursing home residents are estimated to be unbefriended (White *et al.* 2007).
- (2) *Identify alternatives to properly care for the unbefriended:* Studies indicate that diligent searching can locate surrogates for close to half of those initially thought to be unbefriended (Griggons 2010). Even this leaves a significant

number of people who fall into the category. A 2010 Information Brief by the National Long-Term Care Ombudsman Center, titled "Advocating for the Unbefriended Elderly," provides information about several promising practices.⁹⁵ Most of these revolve around finding people to serve as healthcare surrogates for the unbefriended.⁹⁶

- (3) *Create diocesan and parish programs and ministries to better meet the needs of the unbefriended:* Within the Catholic community, some dioceses coordinate parish-based programs where parish nurses or lay volunteers (sometimes using the Befriender Ministry model⁹⁷ or the Stephen Ministries model⁹⁸) visit those who are hospitalized, living in residential care settings, or homebound. These programs could be tapped to train volunteers to help those at risk of becoming unbefriended in a healthcare setting to name health agents. They might also be tapped to locate volunteers willing to serve as agents.

In dioceses without these programs, diocesan bishops or parish pastors should consider establishing ministries that make available a pool of suitably trained persons to serve as surrogate decision-makers capable of being and willing to be assigned powers of attorney. In this way, the Catholic community can take responsibility for its elderly and infirmed brothers and sisters who are often tempted by the fear of overtreatment to have recourse to simplistic alternatives such as the POLST form.

Recommendations for Catholic Healthcare Facilities

1. *Do not accept POLST forms and decline to participate in the POLST paradigm.*⁹⁹ Given the significant flaws in the

POLST paradigm and form and the ethical hazards inherent in their implementation, we think the most prudent policy for Catholic health-care facilities is to not accept POLST forms and to decline to participate in POLST programs. We advise institutional administrators to delineate in writing the principles necessary to make ethically sound advance medical decisions (e.g. explicitly setting forth the distinction between proportionate and disproportionate means of care and introducing the concepts of “medical imminence” and “sufficient moral foresight”). Administrators should formulate specific policies based on those principles, stating that, because of the inherent risks associated with POLST orders, their institution shall not use or recognize POLST forms, nor will it execute any AD that conflicts with Catholic moral teaching.¹⁰⁰ The right of an institution to delineate “Ethical Principles and Policies” regarding EOL treatment and care is recognized in the Patient Self-Determination Act (PSDA).¹⁰¹ Healthcare facilities should provide such written principles and policies to all patients on admission. Following the lead of the bishops of Minnesota, we recommend that healthcare facilities that already have implemented POLST should review their POLST forms and update them as quickly and as much as possible to ensure compliance with patients’ wishes and informed consent, and with Catholic moral principles. Ideally, even after these improvements, such POLST forms would be phased out and replaced with better alternatives. In those few states that obligate providers to comply with POLST orders,¹⁰² doctors and staff should be appraised of the dangers these documents pose and of their primary obligation to

follow the ERDs and institutional principles and policies. In addition, they should be provided assistance on following their consciences as opposed to merely following documents.

2. *Avoid using forms (such as living wills) with a simplistic checkbox format for rejecting treatment options in advance.* These documents may induce people to make hasty decisions without full and informed consent, and minimize the importance of the considerations necessary for sound clinical and ethical decision-making.
3. *Discourage advance decisions to reject non-medically imminent treatments.* This draws attention to the difficulty of securing sufficient moral foresight for persons making these decisions.
4. *Counsel patients to select a healthcare agent and offer them the opportunity to complete a protective durable power of health attorney.*¹⁰³
5. *Enact programs for training medical practitioners and other staff involved in EOL care about:*
 - (a) *the principles and norms taught in ERD nos. 24–26, 28, 56–59 and 57.* Medical and nursing staff should understand the basic criteria for judging rightly whether particular treatment alternatives constitute extraordinary (disproportionate) or ordinary (proportionate) care; and
 - (b) *the benefits and risks of advance decision-making with regard to life-sustaining treatments;* and
 - (c) *preparing patients and surrogates for appropriate in-the-moment medical decisions at the end of life.*
6. *Create alternatives to current inadequate models of end-of-life decision making.* Consider how to promote an EOL culture in your institution that meets the relational, emotional, and spiritual needs of the sick and dying and so

helps to overcome those conditions that give rise to an inordinate felt need to control the precise circumstances of death.

Recommendations for Catholic Physicians

1. *Change your practice.* Avoid promoting inappropriate advance decisions regarding treatment and care at the end-of-life; become knowledgeable about Catholic principles of ordinary vs. extraordinary care; prepare your patients for in-the-moment decisions; address medical problems as they occur, rather than putting your patients on “tracks” based on choices for future life-sustaining treatments.
2. *Make your concerns known.* If you see inadequate approaches to end-of-life care, or even abuses pertaining to POLST or other advance decision-making tools, inform the appropriate administrator(s) at your facilities and inform your own patients about your approach to sound clinical and ethical decision-making at the end of life.
3. *Get involved:*
 - (a) with alternatives that can help to overcome some of the weaknesses of current, inadequate models of EOL decision-making; help create them; use your expertise for the renewal of EOL care;
 - (b) with discussions or initiatives in your state where POLST programs are being proposed or promoted so you can provide a Catholic witness in EOL matters;
 - (c) with promoting authentic Catholic solutions (e.g. Protective Medical Decision Documents,¹⁰³ preparing patients and surrogates for

in-the-moment-of-need decision making, and protecting the doctor–patient relationship against “facilitated” informed consent).

4. *Speak with your bishops and colleagues about the issues:* Faithful Catholic doctors can provide valuable perspectives to bishops about the clinical and ethical dimensions of appropriate—and inappropriate—end-of-life decision-making. Moreover, Catholic doctors may find that their colleagues have some misgivings about POLST, but not the ethical vocabulary to articulate and advance their misgivings. Catholic doctors should be a resource to other physicians and healthcare professionals in discussing ethical concerns and formulating prudential policies to serve the best interests of patients.

Conclusion

There are reasons to believe that the process of dying, already difficult in our contemporary, complex healthcare institutions, may only get harder given the increasing challenges in our culture ranging from rising healthcare costs to ongoing secularization. To respect human life and dignity, we must bring moral commitment, ethical principles, and the highest clinical standards to end-of-life care. We need policies to guide this care and tools to help us implement it. The POLST paradigm and form are too flawed to contribute to these goals, even though they were created with the stated goal of improving end-of-life care. We have proposed some alternatives to POLST, and look forward to working with our colleagues, patients, and fellow citizens to make improved clinical and ethical care at the end of life a reality.

ENDNOTES

1. Pope Pius XII, in an address to anesthesiologists in 1957, introduced the term “ordinary means” to refer to forms of medical care that one is morally obliged to use (see *The Prolongation of Life: An Address to an International Congress of Anesthesiologists*, 1957); the terms “ordinary” (or “proportionate”) and “extraordinary” (or “disproportionate”) were elaborated in the 1980 document of the Congregation for the Doctrine of the Faith, *Declaration on Euthanasia* (sec. IV); the terms “ordinary” and “extraordinary” are also used in the United States Conference of Catholic Bishops, *Ethical and Religious Directives for Catholic Health Care Facilities* (nos. 56 and 57).
2. Although POLST is similar in some respects to traditional Advance Directives (ADs), POLST advocates specifically state that POLST forms are not ADs (e.g., Coleman and Mclean 2012, see note 13, p. 65). This has important legal implications. Federal and state laws specifically direct that ADs cannot be required as a condition to receive health care. Most POLST programs contain no such patient protection. Without such protection, programs actually remove patient choice and control since a POLST could be required for admission or treatment.
3. Other factors include a mindset that treats patients as a collection of conditions that can be addressed without reference to the entire patient, and to the uncoupling of the economics of medicine where the payer is outside of the doctor-patient interaction.
4. We thank Ione Whitlock for much of the research contained in the next 30 footnotes.
5. <http://www.polst.org/about-the-national-polst-paradigm/history/>.
6. Lee Lewis-Husk and Michael Garland, *The First Decade*, ed. Susan W. Tolle and Gary T. Chiodo (Portland, OR: The Center for Ethics in Health Care, Oregon Health Sciences University, 1999), p. 10; cf. Tolle and Tilden (2002).
7. Patrick Dunn of Good Samaritan Hospital in Portland, OR, and ethicist Michael Garland of OHSU and Oregon Health Decisions, convened the *Health Ethics Network of Oregon* (HENO) in the mid-1980s. Dunn wrote in 1992 that it was HENO that identified “a significant problem ... at the interface between acute care and long-term care: residents’ preferences for emergent treatment.” Paramedics arriving at the long-term care facility were unable to find “an indication of the patient’s treatment preference, either orally from the care providers, or from the medical record ... HENO convened [physicians, nurses, long-term care providers and others] interested in this issue.” The MTC was devised “after considerable effort over a period of two years” (see Dunn 1992).
8. Dunn’s (1992) article includes a copy of the MTC as it was in 1992: specified signature of “attending physician”; care level 3 stated “provide” (as opposed to “consider”) medical treatments; Section D directs “oral fluids and nutrition must always be offered.”
9. See “Milestones of the Oregon Polst Program (1990-Present).” In 1996, Dunn et al. were still calling it MTC, but says that focus groups had determined POLST was a better name.
10. The *Center for Ethics in Health Care* at OHSU is also the publisher of “The Oregon Death with Dignity Act: A Guidebook for Health Care Professionals”; see <http://www.ohsu.edu/xd/education/continuing-education/center-for-ethics/ethics-outreach/upload/Oregon-Death-with-Dignity-Act-Guidebook.pdf>. The interconnection between POLST and the right-to-die movement is very troubling; one POLST critic, who’s undertaken considerable research on the links between the two, has said, “if you scratch POLST, you find right-to-die.”
11. The NPPTF recommends that local task forces include a “broad representation” of persons working in the field of health care, including representatives “from EMS, emergency department physicians and nurses, the state long-term care association, the state medical association, the state surveyors, the agency responsible for senior services, the state department of health, the state hospital association, home health association, the state bar association and the state hospice association.” Curiously, however, the national task force

- recommends that “representatives of the disability community or interested right-to-life organizations *can be* consulted as needed and *may not need* to serve on the task force” (emphases added). See <http://www.ohsu.edu/polst/developing/implementation-steps.htm>
12. POLST literature emphasizes the support of physicians, especially in collaboration with local medical societies and other physician-led groups. The support of non-physician health care workers is important, but physician support is “key to the initial institutional culture change ... necessary to establish the POLST paradigm” Sabatino and Karp (2011, 13).
 13. Step 6 on the implementation check list states: “Train social workers, nurses, chaplains, and others to be advance care planning facilitators so that they are comfortable and knowledgeable discussing the POLST Paradigm form.” See <http://www.ohsu.edu/polst/developing/implementation-steps.htm>.
 14. See “Program Requirements”; available at <http://www.polst.org/develop-a-program/program-requirements/>. Endorsed programs must also demonstrate that their forms meet several requirements. These are summarized in a power point at <http://www.polst.org/wp-content/uploads/2013/02/hammes+requiredelements-of-a-revised.ppt> and include the following: (1) form constitutes medical orders that must be followed by health professionals across the continuum of care, (2) form is standardized in format, color and wording; (3) form is primarily used with patients with advanced, progressive illness or those who further wish to define their preferences, (4) form may be used to limit treatment or to express a desire for full treatment, (5) form provides clear direction about the desired response if patient is pulseless and apenic, (6) form allows for clear directions about other life-sustaining treatment, (7) form transfers with the patient, (8) health professionals are trained to use the form, and (9) measures are made to monitor the success of the program and its implementation.
 15. See no. 4 under “Program Requirements”; Level 3 and no. 1 under Level 4; available at <http://www.polst.org/develop-a-program/program-requirements/>.
 16. Sabatino and Karp identify several examples of effective statewide end-of-life organizations: *Coalition for Compassionate Care of California* (<http://www.coalitionccc.org>), *Idaho End-of-Life Coalition* (<http://www.idahoendoflifecoalition.org>) *Community-Wide End of Life/Palliative Care Initiative of New York* (formerly A Better Way Coalition) (<http://www.compassionandsupport.org>), *Tennessee End-of-Life Partnership* (<http://www.endoflifecaretn.org>); see Sabatino and Karp (2011, 13).
 17. *15 States*: California, Colorado, Hawaii, Idaho, Louisiana, Montana, New York, North Carolina, Oregon, Pennsylvania, Tennessee, Washington, West Virginia, Wisconsin, Utah; see <http://www.polst.org/programs-in-your-state/>
 18. *30 States*: Alaska, Alabama, Arizona, Connecticut, Delaware, Florida, Georgia, Illinois, Indiana, Iowa, Kentucky, Maine, Massachusetts, Michigan, Minnesota, Missouri/Kansas (metro region), Nebraska, Nevada, New Hampshire, New Jersey, New Mexico, North Dakota, Ohio, South Carolina, Texas, Vermont, Virginia, Washington, DC, Wyoming; see <http://www.ohsu.edu/polst/programs/state+programs.htm>.
 19. Tolle and Tilden (2002, 316): “The Physician Orders for Life-Sustaining Treatment (POLST) Program was developed and implemented with support from The Greenwall Foundation. Studies of Oregon’s progress and continuing barriers to advance planning were supported by the Meyer Memorial Trust, the Project on Death in America and NIH National Institute of Nursing Research (R01 NR03526). Dissemination of our findings has been supported in part by The Nathan Cummings Foundation and The Robert Wood Johnson Foundation.”
 20. See <http://www.compassionandchoices.org/who-we-are/board-of-advisors/>
 21. The website for Choice appears to be extinct. To view their website as it was in the late 1990s, visit <http://web.archive.org/web/19961031150257/http://www.choices.org/>.
 22. See <http://www.nathancummings.org/grant-programs/health-program-grants/>
 23. See MergerWatch Fact Sheet at <http://community.compassionandchoices.org/>

- document.doc?id=413, authored by Elena Cohen, who was an attorney for the Society for the Right to Die in the 1980s, and is now with *Compassion & Choices*. Funding data are at http://www.nathancummings.net/Health_Grants_2005/CommCat-MergerWatch.pdf and http://www.nathancummings.net/health_grants/HPGLstNov06.pdf. It is not surprising that the POLST model is actively promoted by Compassion and Choices; see <http://www.compassionoforegon.org/services/polst/>
24. United States, Department of Treasury, Internal Revenue Service. "Return of Organization Exempt from Income Tax (Form 990-PF): Open Society Institute," 990 Finder. Foundation Center, 2012. Web.
 25. Grant #37343. Robert Wood Johnson Foundation., "Annual Report," (Princeton, NJ 1998, 65). Report is available online at <http://www.rwjf.org/en/research-publications/find-rwjf-research/1998/04/annual-report-1998-.html>.
 26. <http://us5.campaign-archive1.com/?u=76217e6abc7f11ac3e5fd7629&cid=560bbce60a&e=54cbf2cf98>.
 27. The first proposal for a legal document of the sort was advanced by the Euthanasia Society of America in 1967. The Society's lawyer, Luis Kutner, published an essay that year in which he argued that the right to refuse to be treated by doctors when in *compos mentis*, including with life-sustaining procedures, implicitly contained the right to designate in advance that consent to certain types of treatment should be terminated. Such advanced consent, or rather revocation of consent, would limit physicians from taking further action on behalf of patients' lives "and the patient would be permitted to die by virtue of the physician's inaction" (Kutner 1969, quote on 551). Kutner proposed that the document should be called "a living will" (he also proposed the names: "a declaration determining the termination of life," "testament permitting death," "declaration for bodily autonomy," "declaration for ending treatment," "body trust").
 28. 42 U.S.C. 1395 cc (a).
 29. "POLST differs from an advance directive (living will or health care power of attorney) in that it is an actionable medical order dealing with the here-and-now needs of patients—it can build on an advance directive but can be created for patients without advance directives." Charles P. Sabatino and Naomi Karp, *Improving Advanced Illness Care: The Evolution of State POLST Programs* (Washington, D.C.: AARP Public Policy Institute, 2011), available at <http://assets.aarp.org/rgcenter/ppi/cons-prot/POLST-Report-04-11.pdf>
 30. <http://respectingchoices.org/>.
 31. "The La Crosse, Wisconsin program, operating regionally for several years, has developed a trained "facilitator" model that requires completion of an approved training curriculum by nonphysicians who then serve as facilitators for all stages of advance care planning, including POLST." Sabatino and Karp (2011, 24).
 32. In 1991 four health systems in Wisconsin, Gundersen Clinic, Ltd., Lutheran Health System-Lacrosse (now Gundersen Lutheran), Franciscan Health System and Skemp Clinic, collaborated in a program called "Respecting Your Choices," an aggressive advanced directive education program that included the training and sending out of approximately 120 local nonphysician educators. All health-care organizations had access to nonphysician educators. Over the course of the program, the prevalence of advance directive usage increased from 15 to 85%. 98% of the patients opted to forgo treatment. See review essay by Hammes and Rooney (1998).
 33. <http://www.polst.org/develop-a-program/implementation-steps-and-materials>; http://respectingchoices.org/training_certification/what_certification_is_right_for_me.
 34. <http://lawmrh.wordpress.com/2011/09/09/81-year-old-woman-tattoos-do-not-resuscitate-d-n-r-on-her-chest-just-to-make-sure/>
 35. The POLST movement has been described as the "next stage" in achieving the intent of limiting undesired end-of-life medical care through advance decision-making; Meier and Beresford (2009); see also Tuohey and Hodges (2011).
 36. Susan Tolle, Director of the OHSU Center for Ethics; her quote may be found at: <http://blog.gormanhealthgroup.com/2012/03/14/oregon-leads-the-way-on-end-of-life-planning/>

37. <http://www.gundluth.org/?id=3016&sid=1>
38. <http://blog.gormanhealthgroup.com/2012/03/14/oregon-leads-the-way-on-end-of-life-planning/>
39. E. Christian Brugger develops this criticism in 2011 especially 158–161.
40. John Paul II, “Life-Sustaining Treatments and the Vegetative State: Scientific Advances and Ethical Dilemmas” (2004) (On the “Vegetative State”); available at http://www.vatican.va/holy_father/john_paul_ii/speeches/2004/march/documents/hf_jp-ii_spe_20040320_congress-fiamc_en.html. This teaching was reaffirmed in 2007 by the Congregation for the Doctrine of the Faith (see *Responses to Certain Questions of the United States Conference of Catholic Bishops Concerning Artificial Nutrition and Hydration*, August 1, 2007 and incorporated by the United States Catholic Conference of Bishops into the *Ethical and Religious Directives for Catholic Health Care Services* (ERDs) in 2009 (n. 58); for CDF document see http://212.77.1.247/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_20070801_risposte-usa_en.html
41. This specific scenario was reported recently by a man whose father was choking on a piece of chicken. The nurse called frantically to determine whether to intervene: she was uncertain whether his status was “Do Not Resuscitate.” He was “Full resuscitation.” Fortunately she reached the son in time to successfully intervene. (personal contact, FLS).
42. Fagerlin and Schneider (2004, 30–42) observe that: “In pursuit of the dream that patients’ exercise of autonomy could extend beyond their span of competence, living wills have passed from controversy to conventional wisdom, to widely promoted policy. But the policy has not produced results... Even patients making contemporary decisions about contemporary illnesses are regularly daunted by the decisions’ difficulty... How much harder, then, is it to conjure up preferences for an unspecifiable future confronted with unidentifiable maladies with unpredictable treatments?”
43. See the insightful critique of this model by Perkins (2007).
44. Flygt (2012, 47) misrepresents Brugger *et al.* by suggesting that they argue that “non-signature invalidates a POLST DNR order.” The authors never stated this nor was it their point. They questioned whether designating a patient’s signature on POLST forms as merely optional eliminates an important guarantee of fully informed consent (see Brugger *et al.* (2012, 2)). Flygt goes on to say something revealing. If non-signature invalidates a POLST DNR, he says, then “why doesn’t non-signature invalidate a hospital DNR order, *which is generally not formally consented?*” [emphasis added]. Is he conceding by use of this analogy that the orders on POLST forms need not be “formally consented” to by patients in order to be fully valid?
45. Crafting POLST form language in this way is required policy cited by the National POLST Paradigm Program Requirements: “...Language in the forms should start with positive language. For example, the comfort measures description might read ‘Treat with dignity and respect. Keep clean, warm, and dry. Use medication by any route...’ In the comfort measures section, the forms should avoid wording that starts with negative language and suggests that care and comfort of the patient are not paramount, for example, ‘Do not intubate or transport...’” See <http://www.polst.org/develop-a-program/program-requirements/> under “Form Requirements for Endorsed Programs,” No. 12.
46. The North Carolina MOST uses the more neutral term “medically administered fluids and nutrition.”
47. Concerns about physician controlled decision-making and loss of trust have led to a greater demand for patient information about illnesses and for patients to share in more decisions. This has evolved from most decisions being physician-directed to include various levels of patient preferences. The far end of this continuum is an expression of radical autonomy in which the patient may insist upon certain tests or procedures even when not medically necessary or refuse care altogether. Other steps have been defined in a shared decision-making continuum that gives more options for all involved (see Kon 2010).

48. AMA Code of Ethics, Opinion 8.08 (<http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion808.page>).
49. *Emphasis added*; available at <http://www.ama-assn.org/ama/pub/physician-resources/legal-topics/patient-physician-relationship-topics/informed-consent.page>
50. http://respectingchoices.org/training_certification/on-site_courses/last_steps_acp_%28physician_orders_for_life_sustaining_treatment_%28polst%29_paradigm%29
51. Facilitators increase utilization of advance directives in a given community. This was first demonstrated in 1991 in Wisconsin, where advance directive completion increased from 15 to 85% (Hammes and Rooney 1998); the effect was confirmed in a randomized control trial in Melbourne, Australia in 2010, where 84% of patients who, receiving advance care planning by “trained non-medical facilitators” (based upon the Respecting Patient Choices model, La Crosse, Wisconsin), completed advance directives, compared with 30% in the non-facilitator control group (see Detering et al. 2010).
52. Wisconsin POLST, West Virginia POST, Tennessee POST, Washington POLST, Pennsylvania POLST, Minnesota POLST, Louisiana LaPOST, Hawaii POLST, California POLST, Colorado MOST.
53. Respecting Choices (2007), chapter 4.12. For example, a suggested training script involving decisions on feeding tubes states: “To assist you in making this decision, I’d like to give you some examples of the side effects that can occur because of receiving artificial nutrition and hydration. First, the artificial nutrition that is delivered through tubes often moves out the stomach and slips into the lungs, causing pneumonia. This is called *aspiration*. The artificial hydration that is delivered may also increase the amount of fluid the body has to absorb, causing extra fluid in the lungs, making it more difficult to breathe. The extra fluid also causes congestion in other parts of the body, causing pain and discomfort as well as the need to urinate more frequently.”
54. Respecting Choices, “Tube Feeding: What You Should Know,” fact sheet, 2011; one section reads, “You may have fears about not getting food or water. You may think you will starve or be uncomfortable. This is not true. When food and water are not given, you will die from your chronic illness. You will not feel hungry, and you will receive good care to make you comfortable”. This script has been prepared, of course, without actually knowing what diagnosis or illnesses the patient actually has, if any.
55. “Transforming Healthcare: Advance Care Planning”, Gunderson Lutheran Health System. Available at: <http://www.gundluth.org/upload/docs/TransformACP.pdf>
56. “Death Drugs Cause Uproar in Oregon”, ABC News, August 6, 2008. Available at <http://abcnews.go.com/Health/story?id=5517492&page=1#.UHpgVI7Gbpq>.
57. Response to What is POLST? at <http://www.polst.org>
58. See summaries of research studies at <http://www.polst.org/?s=research> and <http://www.polst.org/wp-content/uploads/2013/02/POLST-Literature-Review.docx>
59. In addition, they refused resuscitation 98% of the time, hospitalization and any medical interventions 62% of the time, intensive care (ICU) 92% of the time, potentially curative antibiotics 57% of the time and feeding tubes 64% of the time (only 2% opted for long-term use of feeding tubes); see Hammes et al. (2012), see p. 83 and table 3, p. 80; cf. Hammes et al. (2010).
60. Susan Hickman, Ph.D, “POLST Research and Evaluation” power point, slide three citing Meyers et al. (2004), available at http://www.slidefinder.net/p/polst_research_evaluation_susan_hickman/hickman-nhpco-research-slides-rev/28067343; and a description of the Meyers et al. study at <http://www.polst.org/wp-content/uploads/2013/02/Summary-Q-Washington-POLST-Nursing-Facility-Project.docx>; the study itself was no longer listed on the updated web site’s list of research studies in 2013 at <http://www.polst.org/?s=research>.
61. Although a 10% chance of recovery compared to certain death may seem low, in *Martin v. Richards*, 531 N.W.2d 70, 75, 192 Wis.2d 156, 167–68 (Wis. 1994), the Wisconsin Supreme Court held a physician liable for failing to disclose tests that could have been run to check for a 1–3%

- possibility of a brain bleed (a complication with serious consequences), after the patient later suffered a disabling stroke.
62. Fagerlin and Schneider, 2004. Fagerlin and Schneider, "Response to letter to the editor, *A Viable Alternative to Traditional Living Wills* from Hickman, SE et al.," *Hastings Center Report* (Sept–Oct 2004), page 6. In 2005, the *President's Council on Bioethics* questioned whether living-will type of documents really ensure that patient preferences are honored: "Data from the Robert Wood Johnson SUPPORT study suggests that many patients filling out living wills are confused about what they are being asked to decide, and vague or misinformed about the purpose and effectiveness of the medical interventions they are being asked to choose among." The Council argued that when people are healthy they may "incautiously" opt for death over disability. But when sickness comes and they are forced to face death, they often change their minds: "There is in fact an extensive body of research showing how poor we are at predicting our own preferences and desires, especially in regard to choices far off in the future. This inability is likely to be acutely present here, since we have no experience deciding how and when to die" (President's Council on Bioethics (2005). *Taking care: ethical caregiving in our aging society*, page 74. http://bioethics.georgetown.edu/pcbe/reports/taking_care/index.html.
 63. Nelson and Tuohey 2011. From Q&A following presentation: Q: "If the patient completes a POA for health care and also completes a POLST, does the POA have the authority to override the POLST?" A: (Fr. John Tuohey) "Here, if the POLST is completed by a physician with the patient, that document supersedes all others. We would not listen to a POA regarding a POLST... As a practical matter, we advise that when a POLST is completed with the patient, the physician recommends to the patient that they inform the POA that they are likely off the hook now for any decision-making – they quite likely won't be needed."
 64. 42 C.F.R. §418.3 defining "terminal illness" for purposes of eligibility for Medicare's hospice benefit.
 65. POLST-Developing a Program, at <http://www.polst.org/develop-a-program/program-requirements/> for Level 3 Endorsed programs and at #1 for Level 4 Mature Endorsed programs.
 66. Fox Valley Coalition for End of Life, *Basic Needs Giving Partnership Grant Application* September 29, 2011 at pages 9–10; and a draft of the same dated September 1, 2012 at page 2; Briggs (2003). <http://www.edc.org/lastacts>.
 67. Guidance for Oregon's Health Care Professionals (August 2011) at http://www.nursepractitionersoforegon.org/associations/11517/files/NPO_POLST-Guidebook2011V2FINALPOLST.pdf.
 68. California Advocates for Nursing Home Reform (CANHR), *Physicians Orders for Life Sustaining Treatment ("POLST") Problems and Recommendations* (2010) at page 5, available at http://www.canhr.org/reports/2010/POLST_WhitePaper.pdf.
 69. Fox Valley Coalition for End of Life, *Basic Needs Giving Partnership Grant Application* September 29, 2011, at 9–10.
 70. Respecting Choices Advance Care Planning Facilitator Course Manual, Chapter 5.
 71. The National Nursing Home Survey: 2004 Current Resident Tables: Table 12 at http://www.cdc.gov/nchs/nnhs/resident_tables_estimates.htm#Demographics
 72. Frequently Asked Questions about the Physician Orders for Scope of Treatment, FAQ #2 at http://www.wvendoflife.org/MediaLibraries/WVCEOLC/Media/professional/faq_post.pdf.
 73. MOLST is the name for POLST in Delaware and New York. The expansion for people with mental disabilities and for children is contained in FAQ at http://delawaremolst.org/?page_id=30
 74. Web site of Children's Hospice & Palliative Care Coalition (CHPCC): Events page available at <http://www.chpcc.org/calendar/polst-beginning-the-coverage-for-pediatrics>
 75. Web site of CHCPP: About Us: Who We Represent at <http://www.chpcc.org/about-us/>
 76. <http://www.ohsu.edu/polst/>
 77. "The term MOLST is generally applied to an end-of-life document, which is intended to be portable and can be relied upon by any health care provider." Letter dated November 14, 2012, from Division of

- Public Health Director to Health Care Providers, available at http://web.archive.org/web/20130115163536/http://www.patientsrights.council.org/site/wp-content/uploads/2012/12/Delaware_MOLST_11_12.pdf.
78. Md. Code Ann. [Health-Gen] §5-608.
 79. NJ Legis 145 (2011) effective 7/1/12; future §§26:2H – 129 – 26:2H – 140.
 80. OAR 847-035-0030 (6) regarding EMTs and OAR 847-010-0110 pertaining to physicians or physician assistants.
 81. MD pending regulation Title 10 DHMH 10.10.21.04. Facilities include assisted living programs, home health agencies, hospices, kidney dialysis centers, and nursing homes. Note that although a MOLST form is required for each patient, the patient need only be offered the opportunity to participate in the process and no patient or surrogate signature is required.
 82. Md. Code Ann. [Health-Gen] §5-608.1 (c) (3).
 83. Md. Code Ann. [Health-Gen] §5-608.1 (d).
 84. The law notes that a facility must comply except as provided in §5-611 (e) or §5-613 (a). Those provisions state that the health care provider need not comply if aware that patient disagrees with the action [§5-611 (e)] and that the provider who intends not to comply shall inform, assist in transfer and comply pending transfer if non-compliance would likely result in death [§5-613 (a)]. Note that this does not address a situation in which compliance would likely result in death.
 85. OAR 847-010-0110.
 86. OAR 847-010-0110.
 87. OAR 847-010-0110, referring to ORS §127.625 (a) (c) and ORS §127.654 (1).
 88. NJ Legis 145 (3f) (2011) effective 7/1/12; future §26:2H – 131.
 89. NJ Legis 145 (0e) (2011) effective 7/1/12; future §26:2H – 137.
 90. NJ Legis. 145 (9e (1)) (2011), effective 7/1/12; future §26:2H – 137.
 91. “Federal law” would refer to the Patient Self-Determination Act of 1991, requiring that health care institutions inform patients of their right to accept or reject medical care offered to them and provide them with an opportunity to create an advance directive reflecting those wishes. It also requires institutions to state their policies regarding advance directives.
 92. An example of this “everything” or “nothing” approach is seen in the *PBS Television Religion and Ethics Newsweekly* entitled “Advance Directives” (Oct 21, 2011) featuring staff and patient from Gunderson Lutheran Hospital, La Crosse, WI. <http://www.pbs.org/wnet/religionandethics/episodes/october-21-2011/advance-directives/9748/>.
 93. Naomi Karp and Erica Wood, “Incapacitated and Alone: Healthcare Decision Making for Unbefriended Older People ABA,” *Human Rights* 31, no. 2 (2004), 20-24, available at http://www.americanbar.org/publications/human_rights_magazine_home/human_rights_vol31_2004/spring2004/hr_spring04_incapacitated.html.
 94. Douglas Silverman, “Serving the Unbefriended Elder Population: Trends, Challenges, and Successes,” Power Point Presentation, 2011 Minnesota Age & Disabilities Odyssey, Mayo Civic Center, Rochester, MN June 21, 2011 accessed at <http://www.mnodyyssey.org/2011/PowerPoint/Monday/McDonnell-B/9-30am/SilvermanOdysseyFinal.pptx> at slide 31. In a large study of ICU admissions at seven hospitals, attending physicians would have considered withdrawing life-sustaining treatment for 37 unbefriended patients if a surrogate had been available. These 37 patients accounted for 1.2% of admissions during the six-month period studied; twenty-five died in the ICU—fifteen after life support was withdrawn, ten died while life support continued. D.B. White, et al., “Life Support for Patients without a Surrogate Decision Maker: Who Decides?” *Annals of Internal Medicine* 147 (2007): 34-40.
 95. This report is available at http://www.ltcombudsman.org/sites/default/files/ombudsmen-support/training/Informational-Brief-on-Unbefriended-Elders_0.pdf
 96. Three approaches are offered for consideration by those seeking to address the health care decision-making needs of people thought to be unbefriended. Two programs address finding people before they become unbefriended in a medical setting and one links them to volunteer advocates afterwards.
 - (1) *Next of Kin Registry*. The next of kin registry (<http://www.nokr.org>) provides a

free tool for securing next of kin information in emergency situations. The registry trains volunteers who visit with people and record their information which is then only shared with law enforcement, emergency responders and medical personnel. They have a faith-based sub-program, described at <http://www.nokr.org/nok/restricted/faith.htm> which appears to require a local government partner. It may be possible to link a program like this with one that would take the next step of helping people complete health care directives and appoint an agent.

(2) *Minneapolis Volunteers of America Unbefriended Pilot Program*. This pilot project was supported in part by grants from the Minnesota Department of Health Services (DHS) and a local foundation (Id. at 7-8). A 2011 presentation by the DHS grantor reported this project developed protocols to identify, locate and support family or decision-makers and served nearly 100 individuals in the metro area. Of those served, 63% completed a health care directive, 80% of which named an agent and 78% had a follow-up conversation with a doctor; (see Douglas Silverman, “Serving the Unbefriended Elder Population: Trends, Challenges, and Successes,” Power Point Presentation 2011 Minnesota Age & Disabilities Odyssey, Mayo Civic Center, Rochester, MN June 21, 2011, accessed at <http://www.mnodyssey.org/2011/PowerPoint/Monday/McDonnell-B/9-30am/SilvermanOdysseyFinal.pptx>).

(3) *Indiana Volunteer Advocates for Seniors Program* This program was founded by a Catholic healthcare system to provide volunteer advocates for unbefriended inpatients in hospitals, nursing homes and hospices. A volunteer advocate serves a patient for up to 90 days so as to avoid the need for a court appointed guardian. Volunteers carry out all the duties of a typical guardian except for finances, including ethical health care decisions and locating appropriate residential facilities for discharge planning. They are court-appointed as limited guardians and complete monthly reports to the court. This comprehensive approach requires volunteers to complete 40 hours of initial training and another 12 hours per year of continuing training. Limiting volunteers to health care decision-

making and ethics, including communication within health care systems could limit training to a day or less. This program is partially funded by grants. (Information about the Volunteer Advocates for Seniors program is available at <http://www.franciscanalliance.org/hospitals/hammond/services/seniors/vas/Pages/default.aspx>)

97. <http://www.befrienderministry.org>
98. <http://www.stephenministries.org>
99. This will also protect nursing and other staff from being forced to conform to POLST orders that violate their consciences.
100. United States Conference of Catholic Bishops, *Ethical and Religious Directives for Catholic Health Care Facilities* (no. 24), 2009.
101. The PSDA requires most health care institutions (but not individual doctors) to provide patients at the time of admission a written summary of their health-care decision-making rights and the facility’s policies with respect to recognizing advance directives; they must if patients have an AD, and document the fact in their medical record if they do; and they may never discriminate against patients based on whether or not they have an advance directive. *It is against the law for them to require either that you have or not have an advance directive* (see http://www.americanbar.org/groups/public_education/resources/law_issues_for_consumers/patient_self_determination_act.html).
102. See Stewards of the Gift of Life: A Pastoral Statement on Physician Orders for Life-Sustaining Treatment (POLST) from the Catholic Bishops of Minnesota, available at <http://www.mncc.org/stewards-of-the-gift-of-life/>
103. Oregon, for example, requires the following: “A physician or physician assistant licensed pursuant to ORS Chapter 677 shall respect the patient’s wishes including life-sustaining treatments. Consistent with the requirements of ORS Chapter 127, a physician or physician assistant shall respect and honor life-sustaining treatment orders executed by a physician, physician assistant or nurse practitioner. The fact that a physician, physician assistant or nurse practitioner who executed a life-sustaining treatment order does not have admitting privileges at a hospital or health care facility where the patient is being treated does not remove the obligation

under this section to honor the order” (Oregon Administrative Rule 847-010-0110: Physicians and Physician Assistants to Honor Life-Sustaining Treatment Orders).

104. One such document is available from the *Patients Rights Council*: <http://www.patientsrightscouncil.org>
105. See <http://www.patientsrightscouncil.org/site/advance-directive-protective-medical-decisions-document/>.

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