

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

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, Christoph 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 et al. (%)
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 Gunderson 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 healthcare 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. Own decision
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. 100
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.