Examining POLST

Edited by Michael J. Sleasman and Michael Cox

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A Special Report of The Center for Bioethics & Human Dignity

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Introduction

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This special report marks the first supplement of Dignitas, the quarterly publication of The Center for Bioethics & Human Dignity. Dignitas began over 20 years ago as the Center's newsletter Dignity, and has expanded to include both bioethical commentary and original scholarship, along with quarterly bioethics news, updates on developments in medicine, science, and technology, and highlights from cultural touch points with bioethics in fiction and film. In the next evolution of Dignitas as a publication, we look forward to periodically offering supplements such as the one before you that explore contentious areas of bioethical inquiry from within a Judeo-Christian Hippocratic framework. For our inaugural special report, we selected a topic of perennial bioethical concern—end-of-life care planning—and focused the discussion on an area of recent controversy within the contemporary Christian bioethical conversation: POLST (Physician Orders for Life-Sustaining Treatment).

Christians have long believed, as the Apostle Paul claims, that death is a defeated enemy. Or as Dietrich Bonhoeffer boldly decreed, "The miracle of Christ's resurrection makes nonsense of that idolization of death which is prevalent among us today." And yet, the current reality remains that our death is an inevitable certainty amidst all the possibilities of our lives. In the broken frailty of our fallen world, we might agree with the philosopher Martin Heidegger, who noted in his seminal work *Being and Time*, that "death is the ownmost possibility" of being.²

This death exists awkwardly in God's creation. It is awkward, precisely because God is the author and giver of life. The story of redemption is a story of the living God offering blessing in the face of the curse's ultimate consequence—our ownmost possibility. Right at the beginning of this redemption story, this incongruity was especially acute: How can the living God dwell near and among a dying people? The answer to this question is offered in what are, to contemporary readers, some of the most obscure of the biblical texts: the laws of Leviticus. The laws regarding skin diseases, mold, and bodily

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discharges seem especially foreign to us. But these laws offered guidance for people to dwell near the living God. Or, stated another way, these laws gave God's people a way to 'deal with' death.

Despite the passage of millennia and the rising power of modern medicine to extend life, we too must still 'deal with' the reality and inevitability of death—the death of friends and family, and ultimately our own demise. Our ability to address the frailties of human life and to delay death through ever advancing medical technologies and interventions has increasingly led to a cultural discomfort and odd ambiguity with death—a strange mix of death-denial and macabre fascination.³ For many, the ravages of death and dying have been sanitized from our everyday lives. Moreover, we find our own mortality difficult to talk about, something that is attested to in many of the following articles and responses.

Yet as our society ages, conversations that force us to deal with death in a particular manner, specifically how we die, become more pressing. Our ever-increasing technological capabilities allow us to prolong life, even if only a sort of bare life might remain. Here we are confronted with the bald reality of needing to talk about how one might die well with all of these medical options before us.

But neither is the church immune to these cultural tensions and tendencies to avoid conversations about death and dying. Unfortunately, many churches are not places that speak openly of how everyday Christians might die well. Where do clergy and laity go to seek wisdom to questions of dying in our advanced medical age? Questions such as: Does Christian hope require that I undergo certain kinds of burdensome or even unwanted treatments? What of the withdrawal of life-sustaining treatments? Am I obligated as a surrogate decision-maker to authorize artificial nutrition and hydration for my relative? What of voluntary stopping of eating and drinking?

Thankfully, ways that our culture deals with death and dying do not reflect current legal, medical, and bioethical conversations. These conversations regarding the ethics and legalities of the end-of-life have been ongoing for centuries. Albert Jonsen reminds us,

From ancient times, everyone—doctors and patients alike—knew that medicine killed and injured. A standing joke called doctors 'unpunishable murderers.' The new medicine, particularly in the forms that sustained living processes, put a new twist on that old, sad joke. Now a patient's continued life could depend on persistent application of the supporting technology.⁵

The conversation continues in the medical literature. A recent "perspective" piece in the *New England Journal of Medicine* argues that end-of-life care should be evidence-based: an old conversation (i.e., end-of-life care) should meet a modern form of an ancient concept (i.e., evidence-based medicine, itself standing in the lineage of observational medicine leading back to Hippocrates and Galen).

Christians, too, have made several recent contributions to the conversation, reflecting a Christian approach to death and dying.⁷ In these venues, and many others, a serious conversation about dying is alive and well—even if it has not reached the awareness of the general public.

Yet even though this ongoing conversation is old, it is still in many ways new to us. The technological advances of our historical moment demand that we continue to engage the conversation. And we find that the conversation can be guided by the familiar paths of bioethical inquiry: What is the role of patient autonomy—even when the patient is unable to express her wishes? How does a physician fulfill her obligation to "do no harm" in the face of death? Should every medical intervention at our disposal be used in the face of imminent death?

We are interlocutors in an ancient conversation—from the laws of the Old Testament to Christian-Hippocratic physicians to more recent conversations ranging from American legal discourse about advance care planning to palliative care. We must talk about dying, about our preferences for end-of-life care, and about what it means to die well. Moreover, we must do so in a way that takes into account the ever evolving armament of increasingly costly medical interventions available to us. And we must do so in such a way that honors the particular dilemmas and complexities of deciding individual end-of-life care. In other words, we must frame the conversation in a way that honors the dignity of the dying individual living in life's final moments.

This special issue of *Dignitas* is offered as a contribution to this broader conversation. More specifically, this issue offers reflection on this relative late-comer to the repertoire of advance care planning options: Physician Orders for Life-Sustaining Treatment. Understanding that this

is an ongoing conversation with diversity of assessments even within the broader framework of commitment to Judeo-Christian Hippocratism, we have sought to offer scholarly treatment of the issue in a dialogical format. Two lead authors (Edward Grant and Lisa Anderson-Shaw) present extended discussions of the POLST Paradigm, unpacking the legal, ethical, and clinical dimensions of POLST in particular and advance care planning in general. Four invited commentaries then offer responses to these lead essays. These commentaries represent a diversity of ecclesial (Roman Catholic and Evangelical) and professional backgrounds (from moral philosophy and bioethics to law and policy, from a clinical ethicist and medical educator to a philosopher/ theologian and lawyer/bioethicist), as well as a spectrum of assessments with respect to the POLST Paradigm itself. While there are areas of disagreement between the various contributors regarding the particularities of the benefits and concerns of POLST, what is shared is striking: each contributor recognizes the importance of actively engaging in conversations, particularly within the church, about end-of-life decision-making in a way that honors the dignity of the person. It is to this end that we offer this first supplement of Dignitas.

- Dietrich Bonhoeffer, Ethics (Minneapolis: Fortress, 2009), 91.
- 2 Martin Heidegger, *Being in Time* (Albany, NY: State University of New York Press, 1996), 243.
- 3 Cf. Ben Peays, "Fantasy Funerals and Other Designer Ways of Going Out in Style," in Everyday Theology: How to Read Cultural Texts and Interpret Trends, ed. Kevin Vanhoozer, Charles Anderson, and Michael Sleasman, 209–226 (Grand Rapids: Baker Academic, 2007).
- 4 Cf. Lucy Bregman, *Preaching Death: The Transformation of Christian Funeral Sermons* (Waco, TX: Baylor University Press, 2011), and Fred Craddock, Dale Goldsmith, and Joy Goldsmith, *Speaking of Dying: Recovering the Church's Voice in the Face of Death* (Grand Rapids: Brazos, 2012).
- 5 Albert Jonsen, *The Birth of Bioethics* (New York: Oxford University Press, 2003), 266. See Edward Grant's overview of this history in his article in this volume, or, for a more extended discussion of the history of advance medical directives, see Edward Grant, "Advance Medical Directives in the Era of Health Care Reform: Who Decides?" *Dignitas* 20, no. 4 (Winter 2013): 1, 4-7, 10-12.
- 6 Scott Halpern, "Toward Evidence-Based End-of-Life Care," New England Journal of Medicine 373, no. 21 (2015): 2001–2003.
- 7 See for instance Rob Moll, *The Christian Art of Dying: Living Fully into the Life to Come* (Downers Grove, IL: InterVarsity Press, 2010), and Allen Verhey, *The Christian Art of Dying: Learning from Jesus* (Grand Rapids: Eerdmans, 2011). Note also the strong critique of contemporary medicine and its orientation toward death in Jeffrey Bishop, *The Anticipatory Corpse: Medicine, Power, and the Care of the Dying* (Notre Dame, IN: University of Notre Dame Press, 2011).



Back to the Future? POLST and End-of-Life Law

Edward R. Grant, JD

CBHD Advisory Board Member

The "POLST Paradigm"¹ represents the latest development in the four-decade American enterprise of legislating standards for the care of terminally ill and permanently incapacitated patients.² Near the outset of this enterprise, the late lawyer and scholar Dennis J. Horan said of the 1976 California living will statute ("Natural Death Act") that it "adds officious burdens to the death bed, encumbers medical decisions with unnecessary additional consultations and creates rather than clarifies legal problems."3 Horan was equally skeptical of the New Jersey Supreme Court's opinion that same year in the case of Karen Quinlan.4 The court, he noted, relied unnecessarily and unwisely on the constitutional right of privacy, whereas existing common-law principles (such as the right to refuse medical treatment) would have provided a sufficient and more effective basis for its decision.5 More recently, Professor Lois Shepherd echoed Horan's conclusion, if not his precise analysis. Proposing that we put an end to end-of-life law, she concludes (as did Horan) that end-of-life treatment decisions should be treated, in law and clinical practice, like other important medical treatment decisions. The corpus of specialized rules and procedures developed in recent decades "may have been useful and even necessary at some point in the development of the law and ethics in this area, but their value has diminished and it is time to let them pass."6

POLST—the common acronym for Physician Orders for Life-Sustaining Treatment—promises to address these dilemmas. The POLST paradigm purports to compensate for the failure of myriad statutes and court cases to produce, in a critical mass of cases, reliable and actionable indicators of a patient's intentions regarding care at the end of life. Ostensibly, POLST is designed to complement, not replace, mechanisms such as living wills, appointment of healthcare surrogates, and advance medical directives (AMDs). Yet, the literature supporting POLST unambiguously promotes the paradigm as

Edward R. Grant, "Back to the Future? POLST and End-of-Life Law," *Examining POLST: A Special Report of The Center for Bioethics & Human Dignity*, supplement, *Dignitas* 22, no. 4 (Winter 2015): S3–S9.

a superior form of advance care planning. Unlike these prior mechanisms, the bright-colored, one sheet POLST form is the "order" of a physician (or, in some states, a nurse practitioner or physician assistant), in clear, direct language, which is immediately actionable. Recourse to POLST will thus alleviate concerns over applying the boilerplate language in a "form" living will, interpreting the generalized instructions in a "customized" advance directive, or seeking approval at every stage (or at every facility transfer) from an appointed surrogate who may, or may not, understand an incapacitated patient's prior wishes.8 If POLST is not explicitly designed to replace the mechanisms created by existing end-of-life law, it is certainly intended to establish a more sound path toward effective end-of-life decision-making. Before examining whether POLST can live up to this ambition, a brief "POLST Primer" is warranted.

A Primer on POLST

The POLST paradigm was designed in the early 1990s to translate into actionable medical orders a patient's wishes regarding three potential treatment options at the end of life: (1) cardio-pulmonary resuscitation (CPR); (2) intubation and ventilator support; and (3) artificially administered nutrition. Originally, the paradigm also included antibiotics as a fourth treatment option, but this has been dropped in many POLST forms. The paradigm was developed by the Center for Ethics in Health Care at Oregon Health & Science University, together with representatives of stakeholder healthcare organizations.

Shortly thereafter, POLST proponents from Oregon and a handful of other states formed the National POLST Paradigm Task Force (NPPTF). The NPPTF determines whether POLST initiatives in other states qualified as "endorsed" POLST programs, or merely as "developing" programs. A state program may reach "endorsed" status—and thus lay full claim to representing the POLST Paradigm—only if it adheres to NPPTF standards (including the specifics of the POLST form), has addressed relevant legal and regulatory issues, and has developed strategies for dissemination and ongoing evaluation of the program within the state. Seventeen states have

"endorsed" programs, two of which (Oregon and West Virginia), have achieved "mature" status. Twenty-eight other states have programs in various stages of development.¹⁰ While there are slight variations in the POLST form from state to state, the basic structure does not vary. Using the Oregon POLST form as an example, Section A calls for a yes/no decision on the use of CPR if the patient is in cardiopulmonary arrest (no pulse or respiration). Section B, titled "Medical Interventions," is designed to guide treatment decisions in other acute situations. It provides three options: (1) "comfort measures only," (2) "limited additional interventions" or "selective treatment" (to exclude intubation/ventilation and ICU care), and (3) "full treatment" (to include intensive care). Section C indicates the patient's preferences for the use of artificially assisted nutrition if the patient loses the capacity to take food and fluids by mouth. Three options are offered: long-term tube feeding; a defined trial period of tube feeding (which may be specified by additional orders on the form); and no tube feeding.

As noted, POLST is designed to complement, not to replace, existing provisions for AMDs, including the appointment of healthcare surrogates. While any adult can execute an advance directive, POLST is recommended only for a patient with a serious health condition or frailty, whose healthcare provider "would not be surprised" if the patient died within 12 months. 11 AMDs, according, to the paradigm, are intended to guide "future" treatment, while POLST is concerned with "current" treatment. A POLST form may be revoked at any time and, according to the paradigm's guidelines, should be revisited whenever there is a significant change in the patient's condition and at time of transfer to another healthcare setting. The legal foundation for POLST varies from state to state. Most states with POLST programs have amended their state codes pertaining to AMDs and/or to do-not-resuscitate orders (DNR) to implement POLST,¹² but not all potential conflicts with state laws on AMDs and DNR have been resolved.¹³

According to the paradigm, a properly-completed POLST form constitutes a contemporaneous recording of patient wishes that is (1) immediately actionable because it is signed by a physician or other provider, (2) easy to follow because it is on a single-page, brightly-colored, standardized form, (3) more comprehensive than a traditional DNR because of the other treatment options it addresses, and (4) transportable from institution to institution, or from institution to home. ¹⁴ Proponents also contend that POLST serves patient autonomy better than traditional forms of AMDs because (1) the form is created after a discussion between the patient and provider when a serious condition has arisen, and thus addresses

current, specific needs, not a hypothetical scenario that may be years off; (2) under POLST protocols, the form should be revised whenever there is a significant change in the patient's condition; (3) the form will travel with the patient, and thus (unlike an AMD that may be in a home safe or lawyer's office) be available when a decision regarding life-sustaining treatment needs to be made; (4) the form is written in precise medical language and signed by a provider, and thus will more likely be honored by other providers when the patient is transferred; and (5) POLST is not subject to the variances, limitations, and formal requirements that afflict current state laws on AMDs and surrogate appointments. 15 Deviance from the requirements of the POLST paradigm would place at risk these lofty objectives. While states frequently amend laws and regulations to accommodate and implement the POLST paradigm, their latitude in doing so is constrained by the mandates enforced by NPPTF. Legislative changes to the structure of the POLST form,16 its status as an "order," or its portability jeopardize the state's ability to achieve "endorsed" POLST status.17 While allowing for minor variations in implementation, POLST is a one-size-fits-all paradigm, implementation of which is zealously guarded by NPPTF.

With this brief background, we can consider POLST's influence on end-of-life decision-making, its relationship to existing legal standards regarding the provision and withdrawal of life-sustaining treatment, and whether the superseding authority intended for the POLST form is appropriate, particularly in non-emergency settings.

POLST and Current End-of-Life Standards

To the first issue, the POLST paradigm proposes a clear answer: if correctly followed, POLST is intended to—and will—change the manner in which end-of-life treatment decisions are made.¹⁸ According to one expert, POLST reflects a growing consensus away from a legalistic, "transactional" model of advance care planning (embodied in living wills and AMDs) toward a patient-centered "communication" model that emphasizes an iterative process of decision-making that focuses on goals of care in light of the patient's current medical condition and personal beliefs and values.¹⁹ A core premise of POLST is that completion of the form is based on the voluntary, informed consent of the patient. However, the paradigm also anticipates that all patients in the target POLST population—those whose death within a year would not be a "surprise"—will be given the opportunity to complete a POLST form.²⁰ For the most part, POLST does not aim to reach this objective through mandates, such as the "mandatory offer" of an opportunity to complete an advance directive required by the federal Patient Self-Determination Act. The vast majority of POLST states do not require that hospitals and other institutions offer POLST to certain categories of patients. Consistent with the paradigm's standards, those that do emphasize participation in POLST is strictly voluntary.²¹ In this way, POLST may be said to adopt a "soft" carrot-and-stick incentive to more open discussion and decisions on end-of-life treatment options.

The Uniqueness of POLST?

No one denies the laudable goal of detailed physician-patient consultations, built on the principles of informed consent, suitable to the clinical situation of the patient. Yet, is the POLST form the most suitable "carrot" to reach

that goal? The format seems to require a particular structure to those discussions, steered toward reaching a "yes" or "no" decision on the listed treatment options—options that may be of limited relevance to a given patient's circumstances, and to the exclusion of options that may be far more relevant. Completion of the form, in the rigid format dictated by NPPTF, is the *sine qua non* of the entire POLST paradigm. NPPTF no doubt intends that any discussion of end-of-life treatment would be tai-

lored to an individual patient's needs. Patients also may decline to respond to any of the options on the form, and may use other instruments, including non-POLST medical orders and AMDs to communicate preferences on other aspects of treatment. But only the POLST orders appear on bright pink card stock, signifying their intended priority and precedence over other patient or provider directives. The underlying intent is manifest—to get as many patients as possible to decide among these options, and to make those decisions actionable as a matter of clinical practice and law. The POLST paradigm is transparent on these points: not enough patients currently state their preferences regarding these core measures of life-sustaining treatment, and of those that do, the lack of enforceability undermines those preferences.

One can readily understand POLST's objective to simplify and "empower" patient choices—particularly on the utilization of CPR and intubation/ventilation, and particularly if the patient has been discharged from acute care to a skilled nursing facility, hospice, or home. A patient who has consented to entry of a DNR order and has chosen to return home for the duration of a terminal illness should be confident that paramedics who may be summoned by a 911 call will not override that order. (The same is true for the discharged patient who desires to be resuscitated, perhaps until death is more imminent.) The availability, clarity, and prominence of a POLST form are

suited to the type of split-second decision that must be made in such a circumstance. The same would be true of a patient discharged to a skilled-nursing facility; the POLST form could limit emergency calls and transfers to acute care that run counter to the desires of the patient.

However, POLST's inclusion of "artificially administered" or "medically assisted" nutrition seems less justified, especially given the breadth of the target POLST population (anyone whose death within a year would not be a "surprise"). Few if any decisions to institute tube feeding are undertaken as an emergency measure. (Although POLST is not entirely clear on this point, we can assume that "artificial nutrition by tube" refers to mechanisms such as a PEG tube and does not include

POLST is recommended only for a patient with a serious health condition or frailty, whose healthcare provider "would not be surprised" if the patient died within 12 months.

use of IV fluids to relieve dehydration.) The inclusion of tube feeding brings POLST into an ethical gray area, as some religious and ethical authorities view the refusal or cessation of tube feeding as tantamount to euthanasia. POLST proponents contend that the range of options on the form accounts for these controversies, and forces no one, patient or provider, to act contrary to conscience; they cite as evidence that some Catholic hospitals participate in POLST.²² But conflict remains. A pastoral letter from the Catholic bishops of Wisconsin concluded that the POLST form "oversimplifies" end-of-life treatment decisions, and, in reference to cessation of tube feeding, may authorize acts that are tantamount to euthanasia.²³ The National Catholic Bioethics Center likewise concluded that Catholic institutions should not accept POLST forms.²⁴ Even setting aside the particular objections in Roman Catholic moral teaching, POLST holds no particular advantage over "ordinary" provider orders or advance directives in guiding decisions whether or not to place a feeding tube. Furthermore, the contemporaneous assent of a duly-appointed surrogate, reflecting the desires stated by the patient in an AMD or in private, may be a far more reliable and ethically appropriate basis on which to base a decision on assisted feeding. POLST instructions may simply repeat the wishes stated in an AMD or conveyed by a surrogate. But they could conceivably conflict—meaning that the process of completing the POLST form should include inquiry into whether

the patient has an AMD and/or has appointed a surrogate, as well as informing the surrogate of the decisions reflected on the POLST form. While the POLST paradigm recommends such a comprehensive approach to discussions with the patient, the form retains its authority whether or not the recommendation is followed. This example illustrates POLST's complex and unresolved relationship with key aspects of existing end-of-life law.

The POLST form is most suited to genuine emergencies and "in the moment" treatment decisions, particularly where existing law requires the use of aggressive life-sustaining treatment.²⁵ The most common scenario involves emergency medical services (EMS) personnel, required by law and protocol to perform aggressive and invasive life-sustaining measures on patients in cardio-pulmonary arrest. All aspects of the POLST form—the standard format, the bright paper, and the clear physician's

...the further the distance from a genuine emergency, the weaker the case for POLST as opposed to other forms of directing patient care, and the greater the potential for conflict with existing laws.

orders—are necessary and sufficient to notify emergency personnel not to apply such measures, or to apply them if the POLST form so indicates. Even here, however, POLST may come into conflict with existing rules on out-of-hospital DNR orders. Virtually all states have adopted protocols for such orders (outside the context of POLST) that may include, depending on the state, both formal and substantive requirements, such as a certification by two physicians that the patient meets a qualifying precondition such as terminal illness or permanent unconsciousness. POLST proponents view such requirements as "barriers" to the implementation of POLST; another perspective might view POLST as undermining safeguards established to protect vulnerable patients and to err on the side of life.

POLST proponents emphasize that "normal" physician-patient conversations reduced to "standard" physician orders are not a viable alternative to POLST during emergency situations.²⁹ However, the further the distance from a genuine emergency, the weaker the case for POLST as opposed to other forms of directing patient care, and the greater the potential for conflict with existing laws. For example, if an assisted living resident or nursing home patient has executed an advance directive

and/or appointed a health care surrogate, what is the need of a POLST form on questions such as the appropriate level of medical intervention or the use of tube feeding? The POLST form, it is argued, is both more contemporary and actionable—but the same would be true of standard physician or provider orders recorded on a medical chart; such orders would also have the virtue of being more detailed and nuanced than the stark, simplistic choices on the POLST form.

POLST & Conflicting Forms

Another difficulty is which advance care form should control—the potentially more detailed AMD, or the more recent and simplistic POLST form? The POLST form attempts to address this prospect by emphasizing (repeatedly, and in bold type) that POLST complements an advance directive, does not replace it, and that both

documents should be examined to ensure consistency. Short of perfect implementation of the POLST paradigm, this will not always be done. What then? State laws differ in their approach to resolving this issue. Some stipulate that the POLST form prevails, others that the AMD prevails. Still others require that the most recently completed document prevails; among this group, California allows a more recent POLST form endorsed by a surrogate to prevail, while New Jersey and Colorado

stipulate that only the most recent patient-created document can prevail.³⁰ The very fact that states see the need to enact such provisions demonstrates that the potential conflict between POLST and other mechanisms such as AMDs is genuine, not speculative.

The authority of a surrogate to complete or override a POLST form also varies from state to state. Healthcare surrogates can be appointed or recognized in several ways: through court-appointed guardianship; through designation by a competent adult of a durable power of attorney for health care (or similar document) under state law; and, in all but a handful of states, through recourse to a "default" list of surrogates designated by statute.31 Some POLST forms recognize a fourth category, a person recognized by the physician as someone who would act and make decisions in the incompetent patient's best interests. The legal authority of this fourth category of surrogates is not as certain as those of the other three, but likely reflects the practical reality when a treatment decision must be made and a formally-appointed surrogate is not available. Surrogates complete over one-third of POLST forms, but some states limit their ability to revoke or modify a POLST form previously completed by the patient when competent.³² Such restrictions may block the "iterative" process that is part of the POLST paradigm, raising the risk that the POLST form becomes stale or "frozen in time."

Finally, the assertion that POLST is intended not to replace AMDs, but to complement them, does not withstand scrutiny. POLST literature typically asserts the superiority of the POLST form over current advance directive and surrogate arrangements, and proposes a template for physician-patient consultation that would render AMDs obsolete.33 The assertion that POLST is not an "advance directive" is even more risible. There are obviously differences between the POLST form and existing AMDs—the AMD, in most states, can be customized in ways the POLST form cannot; the AMD may be executed by any adult, whether young and perfectly healthy or elder and infirm; the AMD is subject to different procedural formalities than POLST; and the AMD is not a physician order. However, the core similarities trump these differences. POLST, like an AMD, is a legal means to communicate patient preferences about contingent future treatment decisions that provides legal immunity to those who in good faith act upon those preferences. The purported distinction between "future" (set forth in AMDs) and "current" (set forth in POLST) treatment directives is blurred by the fact that POLST is not limited to patients with a terminal illness or in imminent danger of death. The pool of patients who may die within a year's time is not defined with particularity, and may overlap significantly with the pool of patients for whom preparation of an advance directive and appointment of a surrogate, all under existing law, would be prudent.

The fact that POLST "ramps up" the statement of patient preferences to the status of physician orders also does not bring POLST outside the ambit of an advance directive. POLST effectively converts into a single step the twostep process of incorporating the preferences stated by a patient, a surrogate, or in an AMD into standard medical orders. Equally tenuous is the claim that the POLST form is a medical order, not (like an AMD), a legal instrument. NPPTF requires specific adjustments to state law in order for a POLST program to be "endorsed," and in response, laws specifically designed to give legal effect to POLST orders tantamount to that of AMDs have been enacted in virtually every state where the paradigm is implemented. POLST, because of its status as a medical order, is a different form of legal instrument from an AMD, but its effect—to record patient preferences for future treatment and provide immunity to those who follow them—is based on the same core principles animating the course of legislation in this area for four decades.

POLST, therefore, is an evolution of, not a departure

from, the long process of actualizing patient preferences in a format that will provide a legal "safe harbor" for those who rely on those preferences. If POLST becomes the dominant paradigm to guide treatment decisions for the terminally and chronically ill, there would be less need to prepare an AMD, save for appointing a healthcare surrogate who, if the need arises, could authorize completion of the POLST form. This would comport with the consensus among many experts that the appointment of a reliable surrogate is the most important element of advance care planning,³⁴ and that such planning should be based on shared communication and shared responsibility between patients, providers, and family members or other surrogate decision-makers.

POLST: Summary of Benefits and Limitations

In its ideal form, the POLST paradigm offers many advantages over the mechanisms previously enacted under the umbrella of "end-of-life law." The "transactional" model embodied in living wills and other forms of AMDs is a defensible starting point for discerning patient values and wishes, but has proven largely ineffective in guiding specific decisions in the clinical setting. In addition, preparation of an AMD in an attorney's office, often many years before it would come into effect, is a weak indicator of patient preference.35 In contrast, the POLST paradigm's objective that the process commence, not with the presentation of the POLST form, but with a detailed discussion of the patient's condition, prognosis, and goals for treatment, is virtually unassailable—as is the expectation that a completed POLST form be revisited when conditions change or the patient is transferred.36 However, short of failure to attain "endorsed" status, there is no mechanism to inform these "musts" within the POLST paradigm, and compliance will inevitably vary.³⁷ Moreover, the raison detre of the paradigm is the entry of physician's orders, and not just any physician's orders, but POLST-compliant orders as defined by NPPTF. Thus, the structured discussions and iterative process mapped out by the paradigm are not ends in themselves, but means to an end.

This would not be a problem if the "end" were more broadly defined to obtain patient-physician (or surrogate-physician) agreement on medical orders appropriate to the patient's present condition, prognosis, values, and preferences. Neither POLST, nor virtually any other aspect of current end-of-life law (save for those provisions allowing personal appointment of a surrogate) is required for this end to be achieved. A patient's right to consent to or refuse medical treatment is secured by common-law, as recognized in numerous state court decisions as well as by the United States Supreme Court.³⁸

Proponents of POLST make a persuasive case that a standardized form is needed to guide the actions of emergency responders. Yet, even here, some caution must be exercised lest POLST becomes a default mechanism for limiting life-sustaining treatment. The case for the necessity of POLST falters when applied to non-emergency situations. Much of *that* case—and it is not negligible—

...autonomy is not an absolute value, and it risks becoming distorted and fetishized if used to diminish the responsibilities we bear in treating the incapacitated.

rests on POLST's practical impact. Published research, while notable for its common authorship by proponents of the paradigm,³⁹ indicates that the paradigm resulted in lower incidence of unwanted CPR, ventilator support, and transfer to intensive care.⁴⁰ In a 2010 study focused on nursing home residents, POLST was reportedly more effective than "traditional practices" in limiting unwanted life-sustaining treatment, particularly those medical interventions addressed by Section B of the standard POLST form.⁴¹ Laudable as they may be, these results do not establish the necessity of POLST; presumably missing in the case of non-POLST patients were clear directives on issues such as hospitalization. POLST may fill this gap, but clearly stated "standard" medical orders should be just as effective.

Conclusion

POLST's growing acceptance signifies recognition that the enterprise of legislating end-of-life law has failed to achieve satisfactory results. Proponents will likely argue that no other mechanism has achieved such widespread acceptance as an alternative to "traditional" methods of effectuating patient preferences. POLST nevertheless risks falling into the same traps as its predecessors. The regimented POLST form is reminiscent of early living wills and standard form AMDs; this necessarily limits its applicability to patients whose treatment dilemmas cannot be reduced to simple "yes" or "no" responses to CPR, hospitalization, and assisted feeding. POLST also manifests the unfounded assumption that special rules and procedures—in copious quantity and exacting detail —are required to permit the withdrawal or withholding of life-sustaining medical treatment. Under current (non-POLST) law, providers are sometimes reluctant to make such decisions unless an AMD is available; in the future, they may be reluctant to act without the execution of a POLST form. For any variety of reasons, a patient in the "POLST pool" may be reluctant to, or simply

delay, authorizing a POLST form to be executed. Does that patient thereby risk being over-treated? Finally, POLST may perpetuate the most regrettable dynamic in our end-of-life law: the search for a talismanic statement ("I would never want to live that way"), document (living will), or other indicator allowing those who actually *make* the decisions about life-sustaining treatment for an

incapacitated patient to believe that the decision is not theirs, but that of the patient. This dynamic is the flip side of our understandable desire to honor patient autonomy. However, autonomy is not an absolute value, and it risks becoming distorted and fetishized if used to diminish the responsibilities we bear in treating the incapacitated.

POLST, to the extent it elicits current patient preferences based on the patient's current condition, is an improvement on what has gone before. Its proponents and overseers (NPPTF), however, should recognize its built-in limitations and, in response, permit greater latitude and flexibility in its implementation. Only then is POLST likely to be a step forward, and not a step back, into the future.

- 1 Thaddeus Mason Pope and Melinda Hexum, "Legal Briefing: POLST: Physician Orders for Life-Sustaining Treatment," *Journal of Clinical Ethics* 23, no. 4 (2012): 353.
- 2 Charles P. Sabatino and Naomi Karp, "Improving Advanced Illness Care: The Evolution of State POLST Programs," AARP Public Policy Institute (2012): 2. Accessible at http://assets.aarp.org/rgcenter/ppi/cons-prot/POLST-Report-04-11.pdf
- 3 Dennis J. Horan, "Editor's Comment on the Living Will," in Death, Dying, and Euthanasia, ed. Dennis Horan and David Mall (Washington, DC: University Publications of America, 1977), 369.
- 4 In re Quinlan, 70 N.J. 10, 355 A.2d 647 (1976).
- 5 Dennis J. Horan, "The Quinlan Case," in *Death, Dying, and Euthanasia*, 525–534.
- 6 Lois Shepherd, "The End of End-of-Life Law," North Carolina Law Review 92, no. 1693 (2014): 1748.
- 7 Pope and Hexum, "Legal Briefing," 354.
- 8 Susan E. Hickman et al., "The POLST (Physician Orders for Life-Sustaining Treatment) Paradigm to Improve End-of-Life Care: Potential State Legal Barriers to Implementation," *Journal of Law, Medicine, & Ethics* 36, no. 1 (2008): 119.
- 9 See National POLST Paradigm, *About the National POLST Paradigm*, http://www.polst.org/about-the-national-polst-paradigm/ (accessed August 18, 2015). See also Pope and Hexum, "Legal Briefing," 355, and Amy Vandenbroucke et al., "POLST: Advance Care Planning for the Seriously Ill," *Bifocal* 36, no. 4 (2015): 91.
- 10 The National POLST website includes an interactive map including information on the status of POLST programs in each state. See http://www.polst.org/programs-in-your-state/.
- 11 Written testimony of Amy Vandenbroucke before Senate Special Committee on Aging, on June 26, 2013, "Renewing the Conversation: Respecting Patients [sic] Wishes and Advance Care Planning," 113th Cong., 10. This testimony can be accessed

- at http://www.aging.senate.gov/imo/media/doc/03_Vandenbroucke_6_26_13.pdf (accessed August 18, 2015).
- 12 National POLST Paradigm Program, *POLST Program Legislative Comparison*, February 15, 2015, http://www.polst.org/wp-content/uploads/2015/03/POLST-Leg-Chart-2-15-15.pdf (accessed August 18, 2015).
- 13 Hickman et al., "The POLST (Physician Orders for Life-Sustaining Treatment) Paradigm to Improve End-of-Life Care," 119.
- 14 Pope and Hexum, "Legal Briefing," 354.
- 15 Ibid. See also Patricia A. Bomba, Marian Kemp, and Judith S. Black, "POLST: An Improvement Over Traditional Advance Directives," *Cleveland Clinic Journal of Medicine* 79, no. 7 (2012): 457–464.
- 16 Oregon stipulates that "the form must not be altered in any way" (their emphasis), and must be printed back to back on "65# Cover Ultra Pink card stock," and for good measure, suggested retailers are offered for obtaining the required paper. http://static1.square-space.com/static/52dc687be4b032209172e33e/t/542ec715e4b0fc638df2bc56/1412351765576/2014.10.02+Printing+POLST+instructions.pdf (accessed August 18, 2015).
- 17 Amy Vandenbroucke, Executive Director of the National POLST Program, testified before a U.S. Senate committee in 2013 that states which modify the POLST form, require patients to be in a "terminal" condition, or mandate completion of POLST forms cannot achieve "endorsed" POLST status ("Renewing the Conversation," 10).
- 18 Mason and Hexum, "Legal Briefing," 354.
- 19 Sabatino and Karp, "Improving Advanced Illness Care," 2-3.
- 20 Vandenbroucke, "Renewing the Conversation," 10.
- 21 Pope and Hexum, "Legal Briefing," 362–63. Maryland and Utah are among the minority of states that require "mandatory offer" of POLST to patients for whom it is suitable.
- 22 Vandenbroucke et al., "POLST: Advance Care Planning," 94.
- 23 The Catholic Bishops of Wisconsin, "Upholding the Dignity of Human Life: A Pastoral Statement on Physician Orders for Life-Sustaining Treatment (POLST)," http://www.wisconsincatholic.org/WCC%20Upholding%20Dignity%20POLST%20Statement%20FINAL%207-23.pdf (accessed August 18, 2015). See also Rev. Javier I. Bustos, "Our Lives on a Bright-Colored Form: A Statement on the Physician Orders for Life-Sustaining Treatment (POLST) Paradigm in the State of Wisconsin," last modified September 8, 2011, http://www.archmil.org/ArchMil/Resources/COMM/OurLivesonaBright-ColoredForm.pdf (accessed August 18, 2015).
- 24 E. Christian Brugger, Stephen L. Pavela, William L. Toffler, and Franklin Smith, "POLST and Catholic Health Care: Are the Two Compatible?" *Ethics and Medics*, 37, no. 1 (January 2012), 1–4.
- 25 Vandenbroucke et al., "POLST: Advance Care Planning," 94.
- 26 Hickman et al., "The POLST Paradigm," 122–123.
- 27 Ibid.
- 28 Stanley A. Terman, "It Isn't Easy Being Pink: Potential Problems with POLST Paradigm Forms," *Hamline Law Revue*, 36, no. 2 (2013): 207–209.
- 29 Vandenbroucke et al., "POLST: Advance Care Planning," 94.
- 30 Pope and Hexum, "Legal Briefing," 362.
- 31 Edward R. Grant, "Advance Medical Directives in the Era of Health Care Reform: Who Decides?" *Dignitas* 20, no. 4 (2013): 1, 4.
- 32 Pope and Hexum, "Legal Briefing," 361.
- 33 For example, in her Senate testimony, Vandenbroucke highlighted the "key differences" between the POLST form and an advance

- directive chiefly by noting that only the latter "needs interpretation," "communicates general wishes," and is not "generally available when needed." The POLST form, by contrast, is "immediately available," communicates "specific" medical treatments, and is "easy to locate" ("Renewing the Conversation," 5). Another commentator asserts that POLST "more accurately conveys endof-life care preferences for patients with advanced chronic illness and for dying patients than traditional advance directives and yields higher adherence by medical professionals." Bomba, Kemp, and Black, "POLST," 464.
- 34 Shepherd, "The End of End-of-Life Law," 1726-1727.
- 35 Angela Fagerlin and Carl E. Schneider, "Enough: The Failure of the Living Will," *Hastings Center Report* 34, no. 2 (2004): 30.
- 36 Sabatino and Karp, "Improving Advanced Illness Care," 2-3.
- 37 Sabatino and Karp have identified a number of barriers to proper implementation of the paradigm, including misperception that POLST is "just another routine form," that the POLST process is cumbersome and time-consuming, and even that emergency medical personnel find the POLST form confusing because of the number of options presented on the form (Sabatino and Karp, "Improving Advanced Illness Care," 18).
- 38 Cruzan v. Director, Missouri Department of Health, 497 U.S. 261 (1990); See also Grant, "Advance Medical Directives," 4.
- 39 See Susan E. Hickman et al., "A Comparison of Methods to Communicate Treatment Preferences in Nursing Facilities: Traditional Practices Versus the Physician Orders for Life-Sustaining Treatment Program," *Journal of the American Geriatrics Society*, 58, no. 7 (2010): 1241–1248; Susan E. Hickman et al., "Use of the Physician Orders for Life-Sustaining Treatment (POLST) Paradigm Program in the Hospice Setting," *Journal of Palliative Medicine* 12, no. 2 (2009): 133–141; Terri A. Schmidt et al., "The Physician Orders for Life-Sustaining Treatment Program: Oregon Emergency Medical Technicians Practical Experiences and Attitudes," *Journal of the American Geriatrics Society* 52, no. 9 (2004): 1430–1434; and Susan E. Hickman et al., "Use of the Physician Orders for Life-Sustaining Treatment Program in Oregon Nursing Facilities: Beyond Resuscitation Status," *Journal of the American Geriatrics Society*, 52, no. 9 (2004): 1424–1429.
- 40 Sabatino and Karp, "Improving Advanced Illness Care," 6-7.
- 41 Hickman et al., "A Comparison of Methods to Communicate Treatment Preferences in Nursing Facilities," 1241-1248.



Physical Death Is Certain and Permanent: A Review of the POLST Paradigm

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Physical death of all human beings is both certain and permanent. We know this to be true. What is not always known is how we will die, where we will die, who will be with us, if we will be in pain, if we have made our end-of-life treatment wishes known to our physician and family, or if we will be aware that death is near. But we will all surely experience death.

We also know that death looks very different now than it did 60 years ago. Medical technology has exploded since the first respiratory ventilator in 1929, the first kidney dialysis machine in 1943, and the first human organ transplant (kidney) in 1954. The technology expansion has also produced great advances in pharmaceuticals and innovative diagnostic and surgical procedures. Modern medicine can now sustain biological life long after the quality and meaningful interactions that give purpose to being human are gone. However, though the technology and innovative advances in medicine are morally neutral, it is the how, why, and for what purpose we use these technologies and medical advances that attribute moral dimensions to them. If we use all of our medical resources to stave off biological death when death is imminent, we are not being good stewards of those resources. We also risk using the individual as a means to an end, rendering the application of such medical resources as immoral.

This article will explore issues related to healthcare and how we die in America, as well as a Christian response to end-of-life treatment decisions, primarily through the use of advance directive documents. Clinical examples will explain the moral application of medical technology, end-of-life care, and the role of advance directives for healthcare in such situations.

Lisa Anderson-Shaw, "Physical Death is Certain and Permanent: A Review of the POLST Paradigm," *Examining POLST: A Special Report of The Center for Bioethics & Human Dignity*, supplement, *Dignitas* 22, no. 4 (Winter 2015): S10–S15.

How We Die in America

When asked where a person would wish to die, most people say they would like to be home with family. Regardless of preferences, however, most Americans die in hospitals or long term care facilities. Indeed, according to the Centers for Disease Control and Prevention, 70% of Americans say they would prefer to die at home, but only 25% actually die at home. The reasons for this disparity are complicated and multi-faceted. One factor includes the lack of discussions with family members about end-of-life (EOL) treatment options and preferences as an illness progresses. Another major factor is that physicians and other healthcare providers may not be asking questions or offering assistance to their patients who have serious illnesses that will likely progress to death. Our culture is generally not comfortable talking about death—and this is true of both providers and patients. Providers say they are not trained to have discussions about death and also they do not want to "take away hope" from their patients by talking about the likelihood of death due to illness and disease.

Case 1: One of my closest friends was diagnosed with breast cancer that had progressed very rapidly over 4 years. She had chemotherapy and radiation treatments, but despite these treatments her cancer spread to her lungs and liver. I would take her out for coffee each week, and as she grew sicker I would go to her home and sit with her and talk as she was able. She knew I was an Advance Practice Nurse (APN) and clinical ethicist and that much of my work was helping patients and family members during end-of-life decisions.

About 6 weeks before she died, I asked her if her doctors had discussed her prognosis and what her death might look like. Surprised, she said, "They have never brought that topic up, and if they don't, I am not going to." She was eventually admitted to the hospital for the last time and transferred to an inpatient hospice two days before she died.

It should not be the sole burden of the patient to initiate important conversations with their doctor about EOL care. Rather, it is the obligation of physicians and providers to begin such conversations when the individual is diagnosed with serious illness that may eventually contribute to death. EOL treatment conversations should include comfort care and specifically palliative care options (making people comfortable through medications or devices); medications and their side effects that will be offered in their treatment (chemotherapy, radiation therapy, medications to assist with any side effects of treatment); supportive care such as social workers, clergy, psychiatric assistance, and physical therapy; and what aggressive treatments would be preferred if needed at EOL, such as ventilators, feeding tubes, and dialysis.

EOL care has been discussed for many years, but has taken on a much greater significance since the 2014 Institute of Medicine (IOM) report, *Dying in America*. In 2011, the IOM released an earlier report on pain management and the inadequacy of healthcare providers in taking care of patient pain.² This led to a major overhaul in the clinical arena regarding how providers assess and treat pain effectively. The *Dying in America* report notes:

For patients and their families, . . . no care decisions are more profound. For the millions of Americans who work with or within the health care sector—clinicians, clergy, other direct care providers, and support staff—the stake is a matter of professional commitment and responsibility. Health system managers, payers, and policy makers also have a professional stake in the provision of end-of-life care that is not only high quality but also affordable and sustainable.³

This report has had profound effects within the healthcare community. We now think about EOL conversations and treatment preferences as one among the other standards of care we are obligated to provide. A medical standard of care is generally noted as a customary practice or clinical care guideline that should be delivered to all persons with a specific illness or condition. Applied to EOL care, the standard of care for individuals with a life-limiting illness or condition includes conversations and information about EOL patient-care preferences. No longer should such conversations be disparaged as a form of "death panel" conspiracy. Even the Centers for Medicare & Medicaid Services (CMS) recognize EOL standards of care are important, as they will begin to reimburse physicians in 2016 for time spent having specific EOL discussions with those patients and families faced with such decisions.

The Process of Medical Decision-Making and the Importance of Advance Directives

Medical decision-making and consent is of great importance in our healthcare experiences. Autonomy has long been an established principle in healthcare and healthcare ethics. A person has the right to make his or her own decisions related to their health and the healthcare they will consent to or refuse. Alternately, paternalism is an approach to healthcare ethics that medical decisions are best made by the physician or provider. Paternalism remains an important principle in healthcare—that is to say, individuals usually seek the opinion of a physician when they have a need to do so. However, it is the autonomous individual who decides if they will follow the physician's recommendation, seek alternative options, or refuse treatment altogether.

In medicine, autonomy is generally accepted as the right of every person to make their own medical decisions, provided they are of legal age, have the capacity to understand the risks and benefits of a specific recommended treatment, and have been informed of treatment alternatives. All other persons must rely on an alternative healthcare decision-maker, often called a surrogate, proxy, or guardian, depending on the situation. Ideally, the alternative healthcare decision-maker will have a history with this individual, will be aware of their values and beliefs, and will have had conversations about this individual's healthcare desires, including possible EOL treatment decisions. However, experience and research indicate that, absent the ability of the person to make their own medical decisions, the alternate decision-maker often is not aware of patient treatment preferences, including EOL care.4 This can become quite uncomfortable for the patient, their decision-maker, and the healthcare team when medical decisions are needed.

When a person lacks decisional capacity to make his or her own healthcare decisions, a proxy decision-maker must be named. Formal advance directives (AD) for healthcare commonly facilitate this. ADs have been in use in various forms for over 45 years. The most common forms include the Living Will (LW), the Durable Power of Attorney for Healthcare (DPAH), and the more recent Physician Orders for Life-Sustaining Treatment (POLST).

Historically, ADs were a result of "patient and consumer rights movements of the 1960s and 1970s when, in response to the successes of intensive care, the United States Supreme Court established that patients have a constitutional right to refuse life-sustaining treatment." The LW allows a person to make known in writing their

preferences for medical treatment in the event that they are terminally ill and expected to live 6 months or less (as assessed by their physician). DPAH, by contrast, allows a person to name a proxy healthcare decision-maker should they become unable to make their own medical decisions. This form also allows the person to write general treatment preferences. ADs generally require the individual's signature with at least one witness to the signature, and do not require a lawyer or notary to execute. All 50 states (and Washington, DC) have both LW and DPAH forms which are honored from state to state. If a person does not have an AD, many states have a for-

mal legal process for naming a surrogate decision-maker, with a priority list for how this surrogate is to be named. With all AD forms, the person and their family, friends, named proxy, and healthcare providers should discuss the wishes of the person and share important information. The most opportune time to discuss AD preferences is when you are healthy and not having any emergent health issues.

Prevalence of lost decision-making capacity is high among persons at the end of life. A recent study of 1,536 persons who were hospitalized near the end of their life showed that 70.3% lacked decision-making capacity. Of these, only 67.5% had an AD of some kind.⁶ Should a person lack capacity to make medical care decisions and not have any AD or person from the surrogate list (often a friend or family member) that can assist with medical decisions, a guardian is then appointed through the legal system. Generally speaking, all persons over the age of 18 should have a DPAH.

Case 2: 25-year-old Susan suffered a severe brain injury after a car accident and was admitted to the neurosurgical unit in critical care. She was taken to surgery where it was discovered that she had a very large bleed within critical areas of her brain. Her surgeons spoke to her husband and parents afterwards and discussed her grim prognosis and that it was not expected that she would ever regain consciousness. Susan had filled out a DPAH form naming her husband as her legal decision-maker. She and her husband had both filled out their AD forms after the death of one of their close friends and discussed their treatment preferences. This helped him and their family make treatment decisions during this very difficult time.

History of POLST Paradigm

As noted above, persons in the United States have a right to refuse life-sustaining treatment. This right may be exercised by the individual patient or, if they lack capacity to do so, may be exercised by their proxy or surrogate decision maker (via AD or guardian). A person's desire to refuse or accept life-sustaining treatment becomes very important should they have a life-limiting disease.

A more recent form of AD that is specifically for persons who have a life-limiting disease and/or a combination of life-limiting and other forms of illness is the POLST form. The National POLST Paradigm originated in Oregon in 1991 as a result of research that found current AD forms "were inadequate for the patients with serious illness or frailty—who frequently require emergency medical care." POLST is a written treatment order that is

ADs, which may include EOL treatment preferences, may be some of the most important decisions in our life and the lives of our family members.

honored across all healthcare settings, including Emergency Medical System (EMS) personnel and First Responder personnel in emergency situations. Most states have a POLST program or are in the midst of developing such programs.

A POLST form is not intended to replace other forms of ADs, but is primarily intended for persons of any age with a serious life-limiting illness and provides medical orders for current treatment as voiced by the person or their legal decision-maker. It is important to note that POLST is meant to be used for the *current* medical situation, which may often include EOL treatment preferences (See Appendix for example of POLST form).

Christian Fears and End-of-Life Decision-Making

As Christians, we are to take care of our body and spirit as precious gifts from God, our Creator. We may take care of our body by healthy eating and getting exercise, sufficient rest, and medical checkups. We take care of ourselves so that we may live out our purpose as God has intended for us—to worship and to do God's work ("For we are God's handiwork, created in Christ Jesus to do good works, which God prepared in advance for us to do" – Ephesians 2:10 NIV).

Maintaining health also includes seeking assistance from wise counselors, such as physicians, to help guide us when we are sick. Guidance with all healthcare decisions is a deliberate and important process between a person and their physician/provider. ADs, which may include EOL treatment preferences, may be some of the most important decisions in our life and the lives of our

family members. Yet many Christians fear that any kind of AD could be misused or corrupted in a way that may dishonor God.

There may be a fear that having an AD might border on a belief in or acceptance of euthanasia, or the deliberate ending of a life by another person using medical means. There may also be confusion between an AD and some state level Death with Dignity statutes, which allow a physician, at the request of a patient diagnosed as terminal, to prescribe a lethal amount of medication that the patient may self-ingest with the intent to cause death.

An additional fear may be that deciding treatment preferences in advance of illness might demonstrate a lack of trust in God to take care of us according to His will when we are ill. As Christians, we believe that all life is sacred and ordained by God, and some may think that making a decision to forego life-sustaining medical treatment at the end of life shows a lack of concern for the sanctity of our own life.

These concerns, and others like them, can be illustrated by a discussion I recently heard on a Christian radio program. One of the commentators described an experience with a physician in the hospital where his father had been admitted. His father had a serious illness and was confined to bed most of the time. The family cared for their father and prayed each day that he would not suffer. On admission to the hospital for an acute illness, the radio commentator was named the decision-maker as his father did not have decisional capacity. The treating physician, as part of the admission assessment, asked the commentator and his family about the Do-Not-Attempt-Resuscitation (DNAR) status of the father. This upset the commentator very much and he went on to describe on air how hospitals have adopted "a culture of death" by asking about possible EOL decisions. Perhaps this is also a fear among Christians in general that our secular society and healthcare systems no longer honor the sanctity of life. However, in my 32 years working in various healthcare settings, I have always found our care providers and clinical teams to work in a culture of life and healing rather than in a culture of harm and death. As Christians, we should honor life, but also not fear physical death and not be so quick to judge questions about EOL treatment preferences.

Catholic Responses to POLST

As might be expected, Christian responses to the POLST paradigm have varied. Within Catholic responses in particular a central criticism of the POLST form is the fear of a slippery slope, such that an individual does not necessarily need to be in the terminal state of health to have

POLST honored by emergency responders, physicians, and healthcare providers, and that perhaps the slope would muddy Catholic teachings that distinguish "between rightful and wrongful refusal decisions by using the terms 'ordinary' (proportionate) and 'extraordinary' (disproportionate) means of medical care."8 Catholic teaching holds that one must "accept ordinary/proportionate means of medical treatment, and may forgo extraordinary/disproportionate means," and as Christian Brugger et al. argue "The POLST model and POLST forms make no distinction between ordinary and extraordinary means."9 The argument is that, by not having such a stipulation directly on the POLST form, there is an inherent and fundamental conflict with the form that cannot be reconciled. In addition, the section of the POLST form related to artificial nutrition (under which a choice may be made by a person to receive or refuse artificial nutrition) may encourage Catholic patients or require Catholic hospitals to make a choice counter to Catholic teaching (per Pope John Paul II in 2004 that artificial hydration and nutrition is morally obligatory until it becomes a disproportionate or burdensome treatment for the person).10

There are Catholic theologians who do not oppose the POLST paradigm. For example, the Illinois Catholic Bishops and the Illinois Catholic Health Association support the use of a POLST form, stating, "Seriously ill Catholics are encouraged to participate actively in decisions about their own healthcare decisions. An individualized, well-crafted Illinois POLST form can provide clear and specific clinical direction based on prior conversations in cases of an emergency where circumstances make conversations impossible."

Criticism of POLST among both Catholics and Protestants is not directed so as to suggest that EOL treatment decisions are unimportant or that such discussions should not be thoughtful and perhaps ongoing between the person, the physician, and their family, but rather that POLST is simply not specific enough for real-time clinical situations, and there is a fear that the form presents a bias toward non-treatment.

When Cure is No Longer the Goal of Care, We Must Always Care

A common reason that physicians call me from the Intensive Care Unit (ICU) for an ethics consult is so I may talk with the family members about their desire for medical treatments that are no longer indicated because the patient is in the active dying process.

Case 3: Laura, a 70-years-old, was admitted to the ICU from the Emergency Department (ED) for weakness and

mental status changes. She had three adult children who were with her in the ED and, since she did not have an AD, and she was not able to make her own decisions at this time, her children acted on her behalf as her legal surrogate decision maker for healthcare decisions. She had been admitted 4 times in the last 6 months for complications of her chronic obstructive pulmonary disease as well as advanced abdominal cancer. She required intubation and

...wedonottalkaboutEOL care preferences or what God's word might have to say about this at church while we are well.

mechanical ventilation in the ED and was sent to the ICU. Though her family took her home from the hospital two months ago with home hospice care, they since changed their mind and now wanted full aggressive ICU care for her, including surgery, blood transfusions, diagnostic tests and even dialysis, should her kidneys fail. Oncology was consulted and had no further cancer therapies to offer and recommended palliative hospice care. Laura was very sick and unconscious and had needed ongoing blood transfusions because she was losing blood from her cancerous abdomen. The ICU team had discussed limitation of further blood transfusions as well as her current status for full resuscitative measures. The team told the family that there was nothing more medically that could be done for Laura and they were committed to keeping her comfortable and allowing a natural death. Her three children continued to tell the ICU team that they had faith in God, their mother was a Christian, and they were waiting for a healing miracle from God.

"Waiting for a miracle from God" is a common phrase I hear at the bedside. Family members wish for treatments that are no longer clinically indicated because they are afraid of losing their loved one to the permanence of death. I often hear family members say that the patient's life is "in God's hands" and that God will take their loved one when He is ready. However, just in case, family members continue to want everything possible done to extend biological life. Another common thread I hear from family members is that "God still has plans for my mother—she is a fighter and I will not give up on her." It is good to call upon God's grace in times of need, but God does not need our medicine or technology in order to provide healing miracles. As Christians, we believe that God has the ability to heal our diseases, and we pray that healing be His will for us and those around us who are sick. God hears our prayers and understands our pain. However, the miracle with which God blesses

us may not be healing or recovery. When family members explain that they want full aggressive care continued in the face of impending death because they are waiting for a healing miracle, I suggest that perhaps the miracle has already occurred, that God has given this day to the patient and family to pray and worship together before God calls their spirit home with Him, as we believe. As Christians, we know that physical death is no longer

our enemy; as Romans 14:8 states, "If we live, we live to the Lord: and if we die, we die to the Lord. So, whether we live or die, we belong to the Lord."

Physicians are not obligated to continue or provide specific treatments if such treatments are not within the standard of care for a specific issue or if it will not provide any medical benefit. Alternately, we as healthcare consumers do not have a right to demand treatments that are not standard of care or clinically indicated. We do have the right to be taken care of appropriately at the end of our life, and our physicians have the obligation to care for us and to palliate our symptoms. Such care is designed to give support to people in the final phase of a terminal illness and focus on comfort and quality of life, with the goal for patients to be comfortable, free of pain, and able to live each day as fully as possible. This is the description of hospice care, but the mere word itself in clinical situations is often translated by patients and family members as "giving up." However, quite to the contrary, palliative care and hospice services with their supportive care and pain management may actually improve quality of life as well as extend life in many cases.12

A Challenge for the Church

As a Christian within a secular society—and as a clinical ethicist in a secular healthcare system—I am extremely mindful of our human community. I am also very aware of God's calling and His desire for us to honor the sanctity of life, to respect His sovereignty, and to be respectful stewards of all our resources. Being good stewards includes how we spend our time and money for God's purposes as well as for our family, community, neighbors, and ourselves. I would argue that being a good steward of our community resources includes being good stewards of our healthcare resources. For healthy individuals, the "collective" cost of care to society (our community, at large) is not very much. However, for individuals with several chronic diseases, debilitation, and frailty, the costs can be extremely high. How might our community meet all the expectations individuals may have regarding medical treatments, especially at EOL, when collective resources are limited and finite?

CMS estimates that over "25 percent of all Medicare spending goes toward the five percent of beneficiaries who die each year." Part of this stems from the increasing percentage of patients using the aggressive treatments of the ICU within the last two to three months of life (up to 33 percent in 2006) with no significant medical improvements and in which death resulted in all cases. "The interventions that do little to stave off death, particularly interventions whose burdens are large compared to their benefits," should have very limited use. 14

Conversations about EOL and how we can respond to death and dying should be part of our church ministries. I have attended many Christian churches in my lifetime and have been blessed immensely by my faith community. Our services often include prayer for those who are sick or in need of help as well as a call for salvation decisions that we may receive the Holy Spirit and receive spiritual eternal life. I would like to challenge our churches to not only speak to our spiritual life but also our physical life. Our churches can be a wonderful platform to have discussions about what decisions may need to be made at the end of our physical life before health crises occur. We find comfort when we are sick and our pastor makes a phone call to us or a hospital visit to pray with us. Our churches minister to us when we are sick and infirmed at the end of our life as well as provide comfort to our family and assistance with bereavement plans once death has occurred. But in my experience, we do not talk about EOL care preferences or what God's word might have to say about this at church while we are well. Our churches should talk about how healthcare can be a culture of life, not a culture of death, and can educate us on what is going on in healthcare related to care choices and decisions.

It is true that modern medicine affords us many amazing and lifesaving treatments and allows us to enjoy our life with our family and friends as well as tend to our spiritual purpose. But modern medicine may also prolong pain and suffering through artificial means when we might otherwise have died naturally. Through it all, God's church feeds our spirit, guides our journey through life, and blesses us as we care for those who are most vulnerable. Our churches offer comfort when we are sick and to our family and loved ones when we die. It is also true that physical death will come to each of us. Yet, our churches do not discuss how we will die. It is how we die and what we discuss about death and dying that I challenge our churches to have a greater voice. Dispelling myths and discussing fears regarding individual preferences for healthcare at the end of life is important, and our churches need to actively participate in this process. Discussing treatment choices and the use of advance care planning tools, such as POLST, should have a place in our faith communities and activities. Making our treatment preferences known to our family through discussions and the use of an AD does not show dishonor to God, rather, it is an act of faith that our lives really are in His hands.

- 1 Associated Press, "CDC Survey Finds Most Americans Prefer to Die at Home," *Journal of Emergency Medical Services*, February 28, 2013, http://www.jems.com/articles/2013/02/cdc-survey-finds-most-americans-prefer-d.html (accessed October 23, 2015).
- 2 Institute of Medicine, Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research (Washington, DC: National Academies Press, 2011).
- 3 Committee on Approaching Death: Addressing Key End-of-Life Issues, Institute of Medicine, Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life (Washington, DC: National Academies Press, 2014), 21.
- 4 Kenneth Covinsky et al., "Communication and Decision-Making in Seriously Ill Patients: Findings of the SUPPORT Project," *Jour*nal of the American Geriatrics Society 48, no. S1 (2000): S187– S193, doi: 10.1111/j.1532-5415.2000.tb03131.x.
- 5 Karen Detering and Maria Silveira, "Advance Care Planning and Advance Directives," *UpToDate*, April 2015, http://www.uptodate.com/contents/advance-care-planning-and-advance-directives (accessed October 23, 2015).
- 6 Maria Silveira, Scott Y.H. Kim, and Kenneth M. Langa, "Advance Directives and Outcomes of Surrogate Decision Making before Death," *The New England Journal of Medicine* 362, no. 13 (2010):1211–1218.
- 7 National POLST, "History," http://www.polst.org/about-the-national-polst-paradigm/history/ (accessed October 20, 2015).
- 8 Christian Brugger et al., "The POLST Paradigm and Form: Facts and Analysis," *The Linacre Quarterly* 80, no. 2 (2013): 113.
- 9 Ibid.
- 10 Ibid.
- 11 Illinois Catholic Healthcare Association, "POLST FAQ," *POLST Illinois*, September 12, 2013, http://www.polstil.org/wp-content/uploads/2013/10/IHCA-POLST-Illinois-FAQs-20130912.docx (accessed October 1, 2015).
- 12 For more information regarding hospice care, visit: National Hospice and Palliative Care Organization, "Hospice Care," July 23, 2015, http://www.nhpco.org/about/hospice-care (accessed October 20, 2015; site now discontinued).
- 13 Helen Adamopoulos, "The Cost and Quality Conundrum of American End-of-Life Care," *The Medicare NewsGroup*, June 3, 2013, http://www.medicarenewsgroup.com/context/understanding-medicare-blog/understanding-medicare-blog/2013/06/03/the-cost-and-quality-conundrum-of-american-end-of-life-care (accessed October 21, 2015).
- 14 Lisa Anderson-Shaw, William Meadow, Hilary S. Leeds, and John J. Lantos, "The Fiction of Futility: What to Do with Policy?" HEC Forum 17, no. 4 (2005): 294.

INVITED COMMENTARY

The POLST Paradigm: Assessing Its Utility and Ethos

Christian Brugger, DPhil

The problem of POLST can be assessed at two levels: utility and ethos. In 2013, ten coauthors and I published a critique of its utility in a *White Paper* for the Catholic Medical Association.¹ We expressed solidarity with POLST proponents in working to overcome the real problems that POLST aims to address, problems associated with ensuring the rightful expression of patient preference in end-of-life care; effectively translating preferences into treatments; and safeguarding a consistent standard of care across care settings. At the same time, we argued that the simplistic form poses significant risks to good medical decision-making and good ethical decision-making, and that neither the form nor the paradigm is an adequate response to those problems.

Utility

One of the more pressing concerns, which neither the essays of Edward Grant nor Lisa Anderson-Shaw (nor of any defender of POLST to date to my knowledge) adequately addresses, is with the intrinsically simplistic mode of medical decision-making represented on the form. The crude check-box format for designating treatment options reduces complex medical decisions to overly simplified scenarios that may not reflect the real-life complexity of end-of-life emergencies; and since these designations may be made weeks or months in advance of a crisis, the POLST encourages some patients indeed tempts them—to make critical life-impacting decisions without all the facts, e.g., the precise details of the condition from which they will be suffering; the reasonable treatment options; and the risks/burdens and promises/benefits of each option. In short, POLST forces decision-making scenarios into a "one-size-fits-all" mold, a virtual "Procrustean bed," ignoring the natural complexities, contingencies and diversity of unanticipated "in the moment" clinical decision-making.

Grant's essay repeats several of our concerns, including the unreliability of the "death within a year" criterion;

Christian Brugger, "The POLST Paradigm: Assessing Its Utility and Ethos," *Examining POLST: A Special Report of The Center for Bioethics & Human Dignity*, supplement, *Dignitas* 22, no. 4 (Winter 2015): S16–S17.

the "ethical gray area" associated with decision-making in regard to the use/refusal of artificial nutrition and hydration; potential conflicts between POLST orders and other advanced medical directives; and the risk that, because the form's directives may not be scrupulously updated, they will become "stale or 'frozen in time." Nevertheless, he thinks that if the implementation of the POLST model is allowed "greater latitude and flexibility," POLST would be "a step forward, and not a step back" in end-of-life care.² This seems to me doubtful.

Anderson-Shaw offers what she refers to as a "Christian response" to problems in end-of-life decision-making, but proposes no critical remarks at all on POLST. Her three case studies do illustrate certain problems, but hardly demonstrate that POLST is the best solution. For as many anecdotes as can be adduced for patients who have suffered unreasonable EOL treatments at the hands of overzealous loved ones, just as many can be found for elderly patients who have suffered under-treatment by clinicians and caregivers whose problematic ideas of autonomy and the "worth" of lives crippled by disability have inordinately influenced their caregiving.

Ethos

POLST is not simply a form. It is, by design, a "paradigm," a model for influencing the culture—ethos—of end of life care. So even if *ex hypothesi* the form's utility could be improved by adding greater latitude and flexibility, the implemented paradigm still would act—and is acting—as a seedbed of values within U.S. healthcare. I will mention just two of several worries I have in this regard.

Neither Grant nor Anderson-Shaw expresses concern with the inevitable marginalization of the physician's role in end-of-life counseling that POLST facilitates.³ POLST defenders claim that the preeminent purpose of the paradigm is to invest the *informed preferences* of patients with clinical efficacy. But the paradigm entrusts the critical role of educating and counseling patients to non-physician "facilitators." This means that information necessary to achieving truly informed consent in matters of life and death—about the likely course that diseases

or other conditions will take, foreseen contingencies, benefits and burdens of available treatment options and their side-effects, etc.—is predominantly communicated by non-physicians: "More often than not the physician role [in the implementation of the POLST process] is to verify the choices made and the process used and then sign off on the orders."⁴

For all our concern today with patient autonomy and informed consent, why is there not more apprehension about the marginalization of physicians? Should red flags not go up when POLST defenders say they want to "simplify" end-of-life decision-making? How can patients make truly informed decisions about care options without being counseled in the facts and complexities of medical situations? Should we not be working to overcome causes of the alienation of the doctor-patient relationship rather than multiplying them?

Both Grant and Anderson-Shaw make a point of noting that POLST is intended for patients who suffer from serious health conditions or life-limiting diseases. But nothing in the paradigm requires this. In fact, POLST model legislation ordinarily abrogates the decades old statutory requirement of Living Will laws that patients must be "terminally ill" before they are authorized to refuse life-sustaining treatment.⁵ By situating refusal requests within the context of death and dying, the older laws implicitly operated from a reasonably limited notion of patient autonomy. The new statutes operate from a virtually unlimited notion of autonomy. When the paradigm was being debated in my home state, the lawyers for the Colorado MOLST coalition stated very clearly at the senate hearing that if their model legislation were enacted any competent adult may refuse life-sustaining measures at any time, for any reason.⁶

POLST literature speaks about "best practice," "improved quality," "reduction of errors," "thoughtful planning," and "respect for patients." But what POLST *does* speaks louder than the mere repetition of words. "Best practice" *should* mean doing what is clinically indicated for patients *under their specific circumstances*. "Quality" should mean best practice *in action*. "Reduced error" should mean best practice in action without confusion, complications, or delay. And "thoughtful planning" should mean that patients ordinarily be assisted *by their physicians* to consider all relevant facts in light of all reasonable treatment options.

But none of these is the aim of the new paradigm. For POLST these positive pithy phrases can be reduced to a single supreme mega-value: the right to refuse treatment without delay or complication across all care settings.

Rather than entrenching Christian healthcare more deeply in the soil of secular values, we should find ways to implement the best possible care available for every patient at the times when he or she most needs it.

Duties of the Dying and End-of-Life Instruments

To Christians, there is something incalculably more important at the end of life than being made comfortable. It is being assisted in every reasonable way possible to do and fulfill the work God has given to them to the end of their lives. Anderson-Shaw gestures in the direction of this theme with her insightful reference to Ephesians 2:10 and her "challenge" to Christian churches. But more needs to be said with respect to the developing of tools and processes for end-of-life decision-making.

What are the duties of dying Christians? . . . To put their earthly affairs in order; carry their crosses with patience; forgive those who need forgiveness and repent to those whom they've wronged; make due provision for their loved ones; direct that proper provision be made for their healthcare if their decision-making capacities erode; offer redeeming love to those around them; and set their eyes on heavenly glory.

Any tool, regimen or paradigm for end-of-life planning should be judged in light of how well it assists patients in carrying out these final duties.

- 1 Christian Brugger et al., "The POLST Paradigm and Form: Facts and Analysis (Catholic Medical Association White Paper)," *The Linacre Quarterly* 80, no. 2 (2013): 103–138.
- 2 Edward R. Grant, "Back to the Future? POLST and End-of-Life Law," *Examining POLST*, supplement, *Dignitas* 22, no. 4 (Winter 2015): S8.
- 3 See the "Respecting Choices" website: http://www.gundersen-health.org/respecting-choices/FAQs and see question on "Why does Respecting Choices support the use of non-physician advance care planning facilitators?"
- 4 Charles P. Sabatino and Naomi Karp, "Improving Advanced Illness Care: The Evolution of State POLST Programs," AARP Public Policy Institute Research Report (2011): 24, http://assets.aarp.org/rgcenter/ppi/cons-prot/POLST-Report-04-11.pdf.
- 5 I develop this criticism with respect to our legislation in Colorado in Christian Brugger, "A Critique of the National POLST Paradigm Through an Analysis of Colorado's New MOST Legislation," *The Linacre Quarterly* 78, no. 2 (May 2011): 157–171, esp. 158–161.
- 6 Ibid., esp. 163.

INVITED COMMENTARY

Bright Pink Forms Are Not Enough

Mary E. Harned, JD

ystopian literature and films have experienced a renaissance in America. In Lois Lowry's critically acclaimed *The Giver*, elderly and other citizens are "released" from life when the government no longer deems them useful. While it is implausible that the U.S. government will begin euthanizing elderly, sick, or disabled Americans, policy makers *are* grappling with how to allocate life-preserving healthcare resources to members of our rapidly expanding elderly population.

In 2016, Medicare will begin reimbursing medical providers for end-of-life counseling, ostensibly to ensure that a patient's wishes regarding treatment are known and followed. Given that most states have or are developing POLST programs,² Medicare end-of-life counseling will often include the opportunity to complete a POLST form with the assistance of a medical provider.³

In her article, "Physical Death Is Certain and Permanent: A Review of the POLST Paradigm," Anderson-Shaw argues that we must be good stewards of healthcare resources and defends the use of advance planning. While Anderson-Shaw addresses some objections to advance planning, she does not focus on a primary concern with the POLST paradigm specifically—that patients will be pressured or even coerced to reject basic life-sustaining care as a cost-containment measure.

Anderson-Shaw states that using "all of our medical resources to stave off biological death when death is imminent" is not good stewardship of those resources.⁴ This sounds unassailable; however, POLST forms are not intended for use only when death is "imminent," and they do not simply designate whether to use or not use extraordinary treatment.

For example, a patient can reject the provision of medically administered nutrition on his POLST form. However, by prematurely making this decision, the patient may forfeit access to quality palliative care that could give him more time. Feeding and hydration do not treat a disease; rather, they meet a basic human need. Without nutrition, a person will die in a short period of time

Mary Harned, "Bright Pink Forms Are Not Enough," *Examining POLST: A Special Report of The Center for Bioethics & Human Dignity*, supplement, *Dignitas* 22, no. 4 (Winter 2015): S18–S19.

regardless of his or her medical prognosis. In contrast, as Anderson-Shaw mentions, "palliative care and hospice services . . . may actually improve quality of life as well as extend life in many cases." A patient who rejects nutrition on a POLST form may not have the capability to communicate a desire to try palliative care when a life-threatening medical emergency arises.

Anderson-Shaw maintains that physicians and providers are obligated to begin conversations about end-of-life care with individuals facing "serious illness that may eventually contribute to death," and that these conversations should not be "disparaged as a form of 'death panel' conspiracy." 8

While individuals facing difficult prognoses can benefit from conversations with trusted healthcare providers about end-of-life care, the tone and timing of the conversations can have a *life-limiting* impact. Patients who are encouraged to complete POLST forms are suffering from terminal or chronic illness or disability. They are making major, life-altering decisions at a time when they are vulnerable and even afraid. As a result, a healthcare provider's assistance in completing a POLST form may have an undue influence over the patient's treatment choices. What's more, the POLST form is then executed as a medical order, available to all of the patient's healthcare providers and even first responders, magnifying the potential impact of the healthcare provider's influence on the patient's decisions.

Anderson-Shaw acknowledges that criticisms of POLST are not aimed at all end-of-life discussions or advance planning, but rather reflect a concern that "POLST is simply not specific enough for real-time clinical situations, and there is a fear that the form presents a bias toward non-treatment." This concern is warranted; further, the widespread use of POLST forms may increasingly be viewed as a legitimate or even expected cost-containment measure. Patients may be pressured into making decisions about end-of-life care based on financial concerns, personal or societal. Further, physicians may feel pressure to make life-limiting recommendations to patients in order to ensure reimbursement from third-party payers.¹⁰

POLST may also be harmful to persons with disabilities

not at the end of life. A task force in Oregon has noted that persons with significant disabilities, developmental disabilities, and/or significant mental health conditions "have been subject to biases resulting in under-treatment and/or had their chronic health conditions mistaken as an illness [sic] nearing the end of life."¹¹

Advance planning, when done voluntarily and with appropriate safeguards (*e.g.*, appointing a durable power of attorney rather than relying upon a written document alone), can be helpful and life-affirming. A patient's loved one who has been informed about her wishes regarding end-of-life treatment, with the aid of a trusted medical professional, can examine all of the facts—many of which cannot be represented on a bright pink form—and can make the best decision for the patient.

- 1 Lois Lowry, The Giver (New York: Houghton Mifflin Co., 1993).
- 2 Lisa Anderson-Shaw, "Physical Death Is Certain and Permanent: A Review of the POLST Paradigm," *Examining POLST*, supplement, *Dignitas* 22, no. 4 (Winter 2015): S12.
- 3 Created first in Oregon in 1991, the "Physician Orders for Life-Sustaining Treatment" (POLST) form was designed "to convert patient preferences for life-sustaining treatments into immediately actionable medical orders" using a "standardized, brightly colored form that provides specific treatment orders

- for cardiopulmonary resuscitation, medical interventions, artificial nutrition, and antibiotics." Susan E. Hickman et al., "The POLST (Physician Orders for Life-Sustaining Treatment) Paradigm to Improve End-of-life Care: Potential State Legal Barriers to Implementation," *Journal of Law, Medicine, & Ethics* 36, no. 1 (2008):119.
- 4 Anderson-Shaw, "Physical Death Is Certain and Permanent," S10.
- 5 See, POLST, "About the National POLST Paradigm," http://www.polst.org/about-the-national-polst-paradigm/ (accessed December 4, 2015): "Only patients with serious illness or frailty, for whom a health care professional would not be surprised if they died within one year, should have a POLST form."
- 6 Anderson-Shaw, "Physical Death Is Certain and Permanent," S14.
- 7 Ibid., S10.
- 8 Ibid., S11.
- 9 Ibid., S13.
- 10 Ibid., S15.
- 11 See Oregon POLST Task Force, "Physician Orders for Life-Sustaining Treatment (POLST) Use for Persons with Significant Physical Disabilities, Developmental Disabilities and/or Significant Mental Health Condition who are Now Near the End of Life," http://www.polst.org/wp-content/uploads/2013/03/POL-STPersonswithDisabilitiesLongDocument.Final_.pdf (accessed December 4, 2015).

INVITED COMMENTARY

To POLST or not to POLST

Robert D. Orr, MD,CM

CBHD Senior Fellow

dward Grant (attorney) and Lisa Anderson-Shaw (clinical ethicist) have addressed advance care planning, and specifically the POLST form (Physician Orders for Life-Sustaining Treatment) from their professional perspectives. Let me start my comments on their work by telling you about Earl.

A few years ago Earl, a healthy man in his 30s, made an appointment to talk with me when I was serving as Director of Clinical Ethics at a large teaching hospital. He was scheduled for a hernia repair in the near future and learned at his pre-admission discussion with a nurse that his advance directive (he had a Living Will) would not be

Robert D. Orr, "To POLST or Not to POLST," *Examining POLST: A Special Report of The Center for Bioethics & Human Dignity*, supplement, *Dignitas* 22, no. 4 (Winter 2015): S19–S20.

recognized as a "Do Not Resuscitate" (DNR) order. He (rather angrily) wanted me to "set her straight," but our time together turned into an educational session about advance care planning.

Grant nicely summarizes the history of advance care planning, its documentation, and both the assistance and barriers imposed on this endeavor by legislative attempts to clarify, formalize and make uniform the process. He identifies several differences between an advance directive and a POLST form, two of which are very important. Earl was not aware of either. (1) An advance directive is generated *by a patient* and is often focused on his or her wishes about limitation of treatment; a limitation of treatment order (including DNR) is written *by a physician* when the clinical situation is consistent with the patient's wishes, and thus requires some interpretation.

(2) An advance directive is about the future and does not take effect until the conditions outlined in the document come to pass; a DNR order is in effect as soon as it is written, no further interpretation needed. Many people, including many healthcare professionals, join Earl in not being aware of this second crucial difference.

Grant looks in detail at some of the statutory and regulatory problems with the increasingly popular POLST forms. In the end he concludes they are an improvement on previous advance care planning documents as long as we all recognize their built-in limitations and as long as their use is limited to situations of serious illness or frailty. He, correctly I believe, is critical of POLST forms for addressing not only resuscitation and intubation, but also artificially administered nutrition and hydration. I suspect this modality is included because of the many media cases and consequent judicial and legislative skirmishes that have generated so much controversy and disquiet. He is right, however, that decisions about the use or nonuse of fluids and nutrition is rarely an urgent matter. This is a matter better addressed in the patient's advance directive rather than the automatically invoked POLST form.

Anderson-Shaw states that physicians have an obligation to discuss end-of-life care when they determine that a patient has a life-threatening illness. She later goes on to suggest that the opportune time to discuss advance directive preferences is when a person is healthy and not facing any emergent healthcare decisions. She also says that all persons over 18 should have a Durable Power of Attorney for Healthcare, thus designating the person they would trust to act as their proxy. I would expand these suggestions to place the onus on the primary physician. Since patients are often reluctant to bring up such matters, I believe the physician should take the initiative in this discussion while the patient is healthy, not just upon the diagnosis of a life-threatening illness. While the patient's wishes may, in fact, change when such a diagnosis is reached, having a "dry run" at such a conversation during an annual health assessment can get the patient used to the idea that this is a legitimate and useful topic of conversation.

Anderson-Shaw includes the POLST form in her list of common advance directives, though she is careful to point out its differences from other directives, much as Grant has done. She supports their use, as do I, in situations of serious illness because of their uniformity and availability, different from other advance care planning documents.

In her role as a clinical ethicist, she goes beyond the utility of advance care planning and POLST forms in the general population to address questions and concerns often raised by Christians. She rightly points out that advance care planning is consistent with our acceptance of the finitude of earthly life, as well as with the biblical principles of sanctity of life and stewardship. She also sympathetically addresses situations in which believers request medically inappropriate treatments because they are "waiting for a miracle." She underlines the palliative care perspective that when there is nothing more that can be done for a patient's illness, there is still a lot that can be done for the patient and their loved ones. She concludes with a challenge to churches to expand their discussion from eternal destiny, as critically important as that is, to include informed discussion about how we die and how we can minister to each other during our final days on earth. I strongly support each of these points.

Edward Grant and Lisa Anderson-Shaw have together provided patients and families with important information and professional insights about the importance of advance care planning.

INVITED COMMENTARY

POLST and Patient-Centered Care: A Commentary on Grant and Anderson-Shaw¹

Carol L. Powers, JD Patrick T. Smith, PhD

CBHD Associate Fellow

Edward R. Grant and Lisa Anderson-Shaw have provided insightful reflections and raised legitimate concerns about the "POLST Paradigm" and its implementation. We are grateful not only for their thought-provoking essays, but also the opportunity to offer the following commentary and response to their perceptive analyses and important observations.

Through her use of cases, Anderson-Shaw does a fine job of implicitly highlighting the important role that narrative plays in thinking about death and dying and the larger metanarrative that shapes those smaller communal stories. "Narrative ethics" is an approach to discourse in bioethics that acknowledges we all come to medical encounters with a story.² Perhaps one of the medical system's responsibilities is to ensure that the patients and families it serves leave the encounter with a "whole story"—not necessarily a "happy ending story," but a narrative that does not harm or destroy. The goal of patient-centered care is to assist in the creation of that whole narrative, leaving patients and families with the sense that they had a voice, they were heard, and their goals and values mattered. It is here that end-of-life medical decisions take on greater weight—there is no "reset button" allowing stakeholders to undo their mistakes and create a better narrative. Too many encounters with the medical system result in prolonged grief, deep anger, or a sense of instability and distrust that last for lifetimes. Avoiding "fragmented stories" is arguably one of the goals of POLST and explicit end-of-life planning.

Slowly but surely, institutional caregivers have attempted to address the narrative aspects of patients' and families' encounters and the medical system has moved, both legally and ethically, toward more patient autonomy and less physician paternalism. Exercising a prima facie principle of autonomy, the patient's purview is to

Carol L. Powers and Patrick T. Smith, "POLST and Patiented-Centered Care: A Commentary on Grant and Anderson-Shaw," *Examining POLST: A Special Report of The Center for Bioethics & Human Dignity*, supplement, *Dignitas* 22, no. 4 (Winter 2015): S20–S22.

convey his or her individual goals of care—what gives that particular person's life value and what kinds of results are expected from any proposed medical interventions? Exercising professional expertise, the physician's purview is to provide medical treatment options that meet those individual goals of care. This new standard of patient-centered care is a shared process, balancing the patient-physician relationship and benefiting both medical and personal outcomes.3 The POLST form is arguably a helpful document to express this balance, setting forth both the patient's values and goals of care as well as describing the physician's available and recommended medical treatment options. The more explicit each patient is about the values which shape their goals of care and the more forthright each physician is about the benefits and burdens of certain life-sustaining treatment options, the more likely it is that "fragmented stories" are avoided by patients and caregivers alike.4

This is not to say there are no real concerns about how the POLST order is entered or implemented. As Grant and others point out, the shortcomings are myriad.⁵ POLST may be presented to patients who are not terminally ill; deficiencies in its signing may occur—e.g., the patient's signature may not be required, it may not be witnessed or notarized, and it may be coerced; presenting a POLST to a patient for consideration may be driven by institutional financial concerns rather than by providing the best care in conformance with the patient's values and goals of care; it may be premature, precluding thoughtful medical decision-making "in the moment"; the physician may not be not required to be involved either in the important explanatory conversation with the patient or in entering the order; and, lastly, the wording of the POLST may bias decisions toward forgoing life-sustaining treatments, putting patients who would opt for certain medical interventions at a disadvantage. Perhaps most importantly, some religious and disability communities have concluded that the perceived bias in the POLST toward forgoing life-sustaining treatment renders the document fatally flawed and dangerous.6 These concerns are significant and must be addressed as

the implementations of the state POLST programs unfold. But the shortcomings of POLST are not fatal and the benefits of the POLST Paradigm in facilitating a conversation about goals of care and treatment options may outweigh the burdens of addressing the deficiencies.

Acknowledging the concerns about POLST of both Grant and Alexander-Shaw, we would make three recommendations to strengthen the POLST Paradigm, most particularly by diminishing any perceived bias toward non-treatment. First, the conversation about life-sustaining treatment options should be sequenced to enhance the patient's ability to understand the ramifications of the choices presented and to provide a truly informed consent. Second, the option of a "trial of therapy" should be highlighted so that the decision either to accept or forgo treatment is not immutable but instead assumes medical decisions will be re-visited and re-evaluated as the patient's medical condition either improves or deteriorates. And third, the provision of both palliative care and hospice services is strongly encouraged.

The sequencing of conversations about end-of-life goals of care and medical planning is best described in the Respecting Choices program established by Gundersen Health System in Wisconsin. Their three-step sequencing approach starts for every adult with the signing of an advance directive, appointing a surrogate decision-maker and providing a description of goals of care based upon values applicable to medical decision-making.⁷ As time passes and an individual's healthcare needs intensify, the patient's surrogate and family members become more involved in the medical decisions being presented to ensure there is an ongoing familiarity with the individual patient's life values and medical goals of care. Finally, when the medical decisions being presented to the patient potentially include more intensive, life-sustaining treatments, then the POLST conversation is initiated by the physician/caregiver. By sequencing these conversations, the patient is best able to express their choices in the context of their current situation, minimizing the distress about POLST forcing decisions made prematurely or through coercion. With such an iterative process, sufficient time is given to all stakeholders to ensure the development of a "whole story." The POLST form does not become an end in itself; rather it is a means to an end, the goal being optimal medical decision-making throughout a patient's life but most particularly at endof-life.

Pursuant to the Massachusetts MOLST (Medical Orders for Life-Sustaining Treatment) program,⁸ the patient is given the opportunity to state their *preferences* for certain medically indicated treatments: (a) intubation and

ventilation, (b) dialysis, (c) artificial nutrition, and (d) artificial hydration. Other treatment options can also be included, such as the use of antibiotics, other medications, blood products, or hospice care. For each of these treatment preferences, options are provided for: (i) no treatment, (ii) to use the particular treatment, (iii) to use the treatment but only on a trial basis for a short term, (iv) undecided, and (v) did not discuss. Having the opportunity to initiate a "time-limited trial of therapy," the patient can be supported by the life-sustaining treatment while a subsequent evaluation of the long-term benefits and burdens of such treatment can be made, avoiding the binary choice of treatment or no treatment.9

Finally, the POLST Paradigm will only be enhanced and strengthened by the provision of either or both hospice and palliative care services. In particular, we would suggest the regulations which underlie the various state POLST programs include specific requirements that: (a) any definition of "palliative care" focus on continued compassionate care; (b) all patients who enter the medical system with either terminal or chronic conditions should begin the conversation with their physicians about recommended medical treatment options and should be offered the opportunity to discuss the POLST document with their physician/caregiver; and (c) all conversations about life-sustaining treatment options must be sensitive to patients' cultural and religious differences and must elicit information about the patient's individual values and goals of care.¹⁰

For the Christian, any discussion of the POLST document and end-of-life medical decision-making must include an acknowledgement of the tensions inherent in our values toward sustaining life, our stand that victory over death has been won, and our confidence that this physical life is not the end of the story. We must balance God's sovereignty with our own individual responsibility; we must understand that suffering produces perseverance while we are simultaneously charged with alleviating suffering; and we see death as both an enemy to be overcome and an enemy already defeated. 11 These tensions, as they relate to end-of-life decision-making and life-sustaining treatments, are often difficult to navigate. To be sure, we need wisdom. Life-sustaining treatments are often technological gifts that allow bodies to heal and vigor to return. But to strive for physical life at all costs can become an idol created by fear. Though it is far from perfect, the POLST Paradigm can help remind us that technology should be subservient to the God of life and death.

We trust the above recommendations regarding the POLST Paradigm—sequencing the medical

decision-making process, providing a trial of therapy option, and ensuring palliative care and hospice services are provided—will help patients and physicians/caregivers better navigate the theological tensions that are necessarily a part of our Christian worldview. May their stories be whole.¹²

- 1 This commentary regarding POLST and end-of-life medical decision-making is based upon our ongoing work both in academic bioethics and clinical ethics consultations. Of course, space limitations do not allow us to fully engage the specific details of the essays.
- 2 Martha Montello, ed. Narrative Ethics: The Role of Stories in Bioethics, special report, Hastings Center Report 44, no. 1 (2014).
- 3 The IOM (Institute of Medicine) defines patient-centered care as: "Providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions." Institute of Medicine, Crossing the Quality Chasm: A New Health System for the 21st Century (Washington, DC: National Academies Press, 2001), 40.
- A legitimate concern exists about how information is conveyed to the patient and the imbalance in power between a patient's exercise of informed autonomy and the physician's description of medical treatment options. Addressing this issue many years ago, the President's Commission for the Study of Ethical Problems in Medical and Biomedical and Behavioral Research issued a report stating: "a professional's careful choice of words or nuances of tone and emphasis might present the situation in a manner calculated to heighten the appeal of a particular course of action."

"It is well known that the way information is presented can powerfully affect the recipient's response to it. The tone of voice and other aspects of the practitioner's manner of presentation can indicate whether a risk of a particular kind with a particular incidence should be considered serious. Information can be emphasized or played down without altering the content. And it can be framed in a way that affects the listener—for example, "this procedure succeeds most of the time" versus "this procedure has a 40 percent failure rate."" The report continues, "Because many patients are often fearful and unequal to their physicians in status, knowledge, and power, they may be particularly susceptible to manipulations of this type." The Presidential Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Making Health Care Decisions: The Ethical and Legal Implications of Informed Consent in the Patient-Practitioner Relationship, vol. 1 (Washington, DC: U.S. Government Printing Office, 1982), 67.

- 5 Edward R. Grant, "Back to the Future? POLST and End-of-Life Law," Examining POLST, supplement, Dignitas 22, no. 4 (Winter 2015): S4-S8; and Stanley A. Terman "It Isn't Easy Being Pink: Potential Problems with POLST Paradigm Forms," Hamline Law Review 36, no. 2 (2013), 177–211.
- 6 Christian Brugger et al., "The POLST Paradigm and Form: Facts and Analysis," *The Linacre Quarterly* 80, no. 2 (2013): 103–138; and Diane Coleman, "Full Written Public Comment: Disability Related Concerns about POLST," submitted on behalf of *Not Dead Yet* to the Institute of Medicine's Committee on Approaching Death, July 23, 2013, http://www.notdeadyet.org/full-written-public-comment-disability-related-concerns-about-polst (accessed January 13, 2016).
- 7 Gundersen Health System, "Stages of Planning," http://www.gundersenhealth.org/respecting-choices/about-us/

- stages-of-planning (accessed January 7, 2016).
- 8 See http://molst-ma.org/download-molst-form (accessed January 13, 2016). Instructions for patients and clinicians are included on this site as well.
- 9 Maria Fidelis C. Manalo, "End-of-Life Decisions about Withholding or Withdrawing Therapy: Medical, Ethical, and Religio-Cultural Considerations," *Palliative Care: Research and Treatment* 7 (2013), 1–5.
- 10 Ibid., 3-4, and Fran London, "Meeting the Challenge: Patient Education in a Diverse America," *Journal for Nurses in Staff Development* 24, no. 6 (2008) 283–285. See also Kleinman's Questions in Arthur Kleinman, Leon Eisenberg, and Byron Good, "Culture, Illness, and Care: Clinical Lesson from Anthropologic and Cross-Cultural Research," *Annals of Internal Medicine* 88, no. 2 (1978):251–258, a summary is available by Namratha Kandula, "The Patient Explanatory Mode," Northwestern University, June 13, 2013, http://www.northwestern.edu/newscenter/stories/2013/06/opinion-health-blog-kandula-.html (accessed January 7, 2016).
- 11 Dennis P. Hollinger, "A Theology of Death," in Suicide: A Christian Response (Grand Rapids: Kregel, 1998), 257–267.
- 12 Cathy Lynn Grossman, "Spelling out Your Views for End-of-Life Care Is a 'Spiritual' Act," *Christian Century*, Nov. 27, 2013, http://www.christiancentury.org/article/2013-11/spelling-out-your-views-end-life-care-spiritual-act (accessed January 7, 2016).

■ HIPAA	PERMITS DISCLOSURE OF DNR/POLST T							
For pati Follow the	State of Illinois Illinois Department of Public Health	O-NOT-RESUSCITA FOR LIFE-SUSTA	INING TREATMENT		DPH DNR.			
For pati	ients, use of this form is completely voluntary. hese orders until changed. These medical orders	Patient Last Name	Patient First N	ame MI	Pols			
ences. A	ed on the patient's medical condition and prefer- Any section not completed does not invalidate the d implies initiating all treatment for that section. gnificant change of condition new orders may	Date of Birth (mm/dd/yy) Address (street/city/state/Z		Gender □ M □ F	-			
need to	be written.				₽			
A Check One	Check □ Attempt Resuscitation/CPR □ Do Not Attempt Resuscitation/DNR □ Do Not Attempt Resuscitation/DNR							
ОНО	When not in cardiopulmonary arrest, follow orders B and C.							
Charle	Level 1 Full Treatment: Primary goal of sustaining life by medically indicated means. In addition to treatment							
One (optional)	described in Selective Treatment and C cardioversion as indicated. Transfer to Selective Treatment: Primary goal of In addition to treatment described in medications (may include ambiotics).	hospital and/or intensive of treating medical cond comfort-Focused Treatme and vasopressors), as me	■ □ □ □ □ □ □ □ □ □ □ □ □ □ □ □ □ □ □ □					
IDPH DNR/POLST	patient preference. Do Not Intubate. Intransfer to hospital, if indicated. Gene Comfort-Focused Treatment: Prima the use of medication by any route as	rally avoid the intensive ry goal of maximizing oneeded; use oxygen, such	NRIPOLST					
	obstruction. Do not use treatments liste Request transfer to nospital only if Optional Additional Orders		-					
Check One (optional)	MEDICALLY ADMINISTERED NUTRITION (if medically indicated) Offer food by mouth, if feasible and as desired. □ Long-term medically administered nutrition, including feeding tubes. □ Trial period of medically administered nutrition, including feeding tubes.							
(optional)	□ No medically administered means of nutrition DOCUMENTATION OF DISCUSSION (below)		HEALTH CARE PROFESSIONALS AS NECES	SSARY FOR TREATMENT		
B D	DOCUMENTATION OF DISCUSSION (Check all appropriate boxes below) □ Patient □ Agent under health care power of attorney □ Parent of minor □ Health care surrogate decision maker (See Page 2 for priority list)				NFORMATIONAL PURPOSES ONLY** Patient First Name	MI		
	Signature of Patient or Legal Represe Signature (required)	Name (print) Date			Not Resuscitate (DNR)/Practitioner Orders for L vour wishes for medical treatment in your curr	Life Sustaining Treatment		
IDPH DNR/POLST	Signature of Witness to Consent (Witness required for a valid form) I am 18 years of age or older and acknowledge the above person has had an opportunity to read this form and have witnessed the giving of consent by the above person or the above person has acknowledged his/her signature or mark on this form in my presence. Signature (required) Name (print) Date				nanged to reflect your new wishes at any time ay need to be made. The Power of Attorney it ay apable adults, regardless of their health statu uctions and name a Legal Representative to	e. However, no form can for Health Care Advance as. A POAHC allows you		
-	Signature of Attending Practitioner (ph	vsician, licensed resident (second	■ nce Directive Information	nt Preference Declaration				
Ε	My signature below indicates to the best of my knowledger. Print Attending Practitioner Name (required)	ge and belief that these orders are	owing advance directives (OPTIONAL)					
/POL		()	Phone Ill Declaration Mental Health Treatment Preference Declaration Contact Phone Number					
IDPH DNR/POLST	Attending Practitioner Signature (required)		Date (required)	<u> </u>				
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■ SEND A	COPY OF FORM WITH PATIENT WHENEVER TRANSF	ERRED OR DISCHARGED • C	Preparer Title	R IS ACCEPTABLE • 2015	Date Prepared			
Completing the IDPH Do Not Resuscitate (DNR)/POLST Form The completion of a DNR/POLST form is always voluntary, cannot be mandated and may be changed at any time. A DNR/POLST should reflect current preferences of persons on pleting the DNR/POLST Form; encourage completion of a POAH Verbal/phone orders are acceptable with follow-up signature by attending physician in accordance with facility/community polic Use of original form is errouraged. Photocopies and faxes on any color of paper also are legal and valid forms. Reviewing a Do Not Resuscitate (DNR)/POLST Form This DNR/POLST form should be reviewed periodically and if: The patient is transferred from one care setting or care level to another, or there is a substantial change in the patient's health status, or the patient's treatment preferences change, or the patient's primary care professional changes.								
								Voiding or revoking a Do Not Resuscitate (DNR)/POLST Form A patient with capacity can void or revoke the form, and/or request alternative treatment. Changing, modifying or revising a DNR/POLST form requires completion of a new DNR/POLST form. Provide in through sections A through E and write "VOID" across page if any DNR/POLST form is replaced or becomes in Beneath the written "VOID" write in the date of change and re-sign. If included in an electronic medical record, follow all voiding procedures of facility.
		CS 40/25) Priority Order 5. Adult sibling union 6. Adult grandchild 7. A close friend of the patient 8. The patient's guardian of the	aced or becomes invalid.					
For more information, visit the IDPH Statement of Illinois law at http://www.idph.state.il.us/public/books/advin.htm								
	rm is available at http://	DPH DNR	For more information, visit the IDPH Statement of Illinois law at http://www.idph.state.ii.us/public/books/advin.htm HIPAA (HEALTH INSURANCE PORTABILITY AND ACCOUNTABILITY ACT of 1996) PERMITS DISCLOSURE TO HEALTH CARE PROFESSIONALS AS NECESSARY FOR TREATMENT Page 2					
_	olstil.org/wp-content/ ls/2015/01/dnrform.pdf	·	SEND A COPY OF FORM WIT	TH PATIENT WHENEVER TRAN	ISFERRED OR DISCHARGED • COPY ON ANY COLOR OF PA	•		

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The Center for Bioethics & Human Dignity (CBHD) is a Christian bioethics research center at Trinity International University that explores the nexus of biomedicine, biotechnology, and our common humanity. Within a Judeo-Christian Hippocratic framework, CBHD fosters a distinctly Christian conception of bioethics that is both academically rigorous and broadly accessible. As a center of rigorous research, theological and conceptual analysis, charitable critique, and thoughtful engagement, we seek to anticipate, interpret, and engage the pressing bioethical issues of our day.

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