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## It Isn't Easy Being Pink: Potential Problems with POLST Paradigm Forms

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## IT ISN'T EASY BEING PINK: POTENTIAL PROBLEMS WITH POLST PARADIGM FORMS

*Stanley A. Terman*<sup>\*</sup>

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## I. INTRODUCTION

### A. Overview

The National Physician Orders for Life-Sustaining Treatment (POLST) Paradigm program is becoming one of the most widely accepted ways to express patients' end-of-life treatment preferences. At present, only five states (Alabama, Arkansas, Mississippi, Oklahoma, South Dakota) and Washington, D.C. do not have an established or developing POLST program.<sup>1</sup> The focal point of the POLST Paradigm is the POLST form, which sets forth the kinds of medical treatment patients will or will not receive toward the end of their lives. Many POLST forms are printed on vibrant pink paper, to draw attention to their presence in likely voluminous patient charts or medical records.

This essay considers six potential problems associated with the use of POLST Paradigm forms: They (1) may not be effective; (2) may not be moral; (3) may not reflect patients' wishes; (4) may not be constitutional (or may not be consistent with state laws); (5) may be clinically dangerous; and (6) may open the door to opportunistic abuse. At worst, using POLST forms

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<sup>1</sup> *Programs in your State* (color-coded map), PHYSICIAN ORDERS FOR LIFE-SUSTAINING TREATMENT PARADIGM, <http://www.polst.org/programs-in-your-state/> (last visited June 27, 2013). See also personal communication on file with the author regarding Nebraska and Alaska.

may lead to inappropriate treatment decisions that contribute to the patient's premature death.

To address the word "potential": the problems that this essay considers are not inevitable, may occur infrequently, or may occur even without the use of POLST forms. For some problems, we have only theory, anecdotes, or reports on small numbers of patients—not statistically significant data. For purposes of beginning discussions, this essay includes the author's opinions regarding whether POLST forms, or the laws that created them, or the way these forms can be and are used, are responsible—in whole, in part, or not at all. The essay also offers for consideration specific recommendations that may lessen or avoid these potential problems.

### ***B. Background***

POLST Paradigm forms translate patients' wishes into immediately actionable physician orders. The acronym POLST stands for "Physician Orders for Life-Sustaining Treatment."<sup>2</sup> This exact term is used by the National POLST Paradigm program and several states.<sup>3</sup> Other states have similar terms and acronyms. The three main goals of the POLST Paradigm are to ensure that a seriously ill person's wishes regarding life-sustaining treatments are (1) known, (2) communicated, and (3) honored across all health care settings.<sup>4</sup>

States do not require clinicians to use POLST forms, but some states require health care providers to comply with the physician orders written on such forms. In California, "[a] health care provider shall treat an individual in accordance with a Physician Orders for Life Sustaining Treatment form."<sup>5</sup> This requirement strives to fulfill the final component of the vision: to honor the person's wishes. However some states allow clinicians to refuse to comply based on a personal conflict with their moral conscience or religious beliefs, as is common for Advance Directives. Some states also allow clinicians to refuse to comply if the "Physician Orders for Life Sustaining Treatment form requires medically ineffective health care or health care contrary to generally accepted health care standards applicable to the health care provider or institution."<sup>6</sup>

The first component of the vision, "to ensure wishes are known," is best fulfilled if clinicians ask patients to express what treatments they would or would not want for possible future conditions. Arguing that the POLST

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<sup>2</sup> *About the National POLST Paradigm*, PHYSICIAN ORDERS FOR LIFE-SUSTAINING TREATMENT PARADIGM, <http://www.polst.org/about-the-national-polst-paradigm/> (last visited May 9, 2013).

<sup>3</sup> *Id.*

<sup>4</sup> *See generally Updated Goals Statement for the NPPTF*, PHYSICIAN ORDERS FOR LIFE-SUSTAINING TREATMENT PARADIGM, <http://www.polst.org/updated-goals-statement-for-the-npptf/> (last visited May 9, 2013).

<sup>5</sup> CAL. PROB. CODE § 4781.2(a) (West 2012).

<sup>6</sup> CAL. PROB. CODE § 4781.2(b) (West 2012).

Paradigm is “more than a form,” the National POLST Paradigm program emphasizes the “POLST Conversation”<sup>7</sup> as the context in which patients’ wishes can be elicited. When treating physicians subsequently sign completed forms, the process could be characterized as obtaining informed consent *in advance*, for the treatment of future medical or mental conditions (which works most effectively if those future conditions can be specifically described).

While POLST Paradigm forms emphasize they are “immediately actionable orders,” many of the orders, in fact, apply to future contingencies. Here are four examples: “IF there is no pulse or no breathing” (e.g., a future cardiac arrest); “IF comfort needs cannot be met in current location” (e.g., to manage future extreme pain); “Transfer to hospital IF indicated. Includes intensive care” (where ‘IF’ means a deteriorating medical condition that requires such intense treatment); and, “Always offer food by mouth IF feasible” (where ‘feasible’ means the patient’s future condition requires assisted oral feeding but can still swallow so is not a high risk for aspiration pneumonia).<sup>8</sup> In general, to obtain informed consent, clinicians are obligated to present to patients all reasonable, available options and to explain the relative risks and benefits of each.<sup>9</sup> Only then can patients (or their surrogate decision-makers) make prudent choices regarding treatment for the last chapter of their lives. This essay discusses whether or not the implementation of POLST Paradigm forms generally fulfills this standard of patient care.<sup>10</sup>

The second component of the POLST vision, “to ensure wishes are communicated,” requires a form structured to provide an effective way for patients to communicate their treatment preferences to other physicians and clinicians so providers will know what actions to take. It is of great importance to some patients that their end-of-life wishes be communicated durably. This is the primary reason why patients engage in advance care planning. They want others to honor their written expression of their end-of-life treatment preferences durably, after they can no longer speak for themselves.<sup>11</sup>

The basis for this belief, which may be naïve, comes from the popularization of patients’ rights, for which there are several relevant sources. Common law guarantees the right to determine what happens to one’s body; that is, the right of self-determination to accept or refuse invasion of one’s bodily integrity. In various contexts, constitutional law protects the rights to privacy, to liberty, and to avoid unusual or cruel

<sup>7</sup> California POLST, POLST Community Presentation 4 (2011).

<sup>8</sup> See, e.g., California POLST Form (2011), [http://www.capolst.org/documents/CAPOLSTform2011v13web\\_005.pdf](http://www.capolst.org/documents/CAPOLSTform2011v13web_005.pdf) (last visited May 9, 2013).

<sup>9</sup> See *Informed Consent*, AM. MED. ASS’N, <http://www.ama-assn.org/ama/pub/physician-resources/legal-topics/patient-physician-relationship-topics/informed-consent.page> (last visited May 9, 2013).

<sup>10</sup> See *infra* Part II.

<sup>11</sup> Advance Care Planning, NAT’L INST. ON AGING, <http://www.nia.nih.gov/health/publication/advance-care-planning> (last visited May 9, 2013).

punishment, which can be interpreted to include freedom from the burdens and pain caused by unwanted treatment interventions.<sup>12</sup> Consistent with this interpretation is a 1992 ruling by United State Supreme Court Justices O'Connor, Kennedy, and Souter that included the following statement:

These matters, involving the most intimate and personal choices a person may make in a lifetime, choices central to personal dignity and autonomy, are central to the liberty protected by the Fourteenth Amendment. At the heart of liberty is the right to define one's own concept of existence, of meaning, of the universe, and of the mystery of human life. Beliefs about these matters could not define the attributes of personhood were they formed under compulsion of the State.<sup>13</sup>

Federal law requires most health institutions to inform patients that they may complete Advance Directives according to their state's law(s).<sup>14</sup> State laws often consider violating bodily integrity without consent to be the crime or tort of battery.<sup>15</sup> Some state laws also withdraw the immunity physicians would otherwise enjoy, if they write orders that are not consistent with the known wishes of patients.<sup>16</sup> For example, under California law:

A health care provider who honors a request regarding resuscitative measures is not subject to criminal prosecution, civil liability, discipline for unprofessional conduct, administrative sanction, or any other sanction, as a result of his or her reliance on the request, if the health care provider (a) believes in good faith that the action or decision is consistent with this part, and (b) has **no knowledge that the action or decision would be inconsistent** with a health care decision that **the individual** signing the request **would have made** on his or her own behalf under like circumstances.<sup>17</sup>

Thus, failure to honor a patient's living will may make physicians vulnerable to malpractice suits and administrative sanctions impacting their professional license.<sup>18</sup> In theory, criminal prosecution is also possible.

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<sup>12</sup> *E.g.*, *Cruzan v. Director*, 497 U.S. 261 (1990).

<sup>13</sup> *Planned Parenthood v. Casey*, 505 U.S. 833, 852 (1992).

<sup>14</sup> Patient Self Determination Act of 1990, 42 U.S.C. §1395cc (2011).

<sup>15</sup> *See, e.g.*, CAL. PENAL CODE § 242 (West 2013).

<sup>16</sup> CAL. PROB. CODE § 4782 (West 2013).

<sup>17</sup> *Id.* (emphasis added).

<sup>18</sup> Holly Fernandez Lynch, Michele Mathes & Nadia N. Sawicki, *Compliance with Advance Directives*, 29 J. LEGAL MED. 133 (2008). *See also* *Anderson v. St. Francis-St. George Hosp.*, 671 N.E. 2d 226 (1996). Future litigation may determine if such rights suffice

External factors can affect physician compliance with Advance Directives. Some physicians believe their judgment supersedes previously-specified patient instructions, including but not limited to medical conditions they contemporaneously consider reversible.<sup>19</sup> Advance care planning strategies can enhance the durability of Advance Directives—even to the point of irrevocability. One example is to establish a bilateral contract-type of relationship between the patient and her durable power of attorney for health care (DPOAHC) that designates an agent whose role is to: “Make sure others will honor my Known Wishes (as expressed in my living will).”<sup>20</sup>

The potential problems in using POLST Paradigm forms arise partly because the vision of the POLST Paradigm is so ambitious. For example, the program tries to serve the needs of several kinds of patients. Clinically, they may be acutely or chronically ill; or just elderly and frail; and either possess or lack capacity. Also, they may, or may not be religious. Some will arrive at the last chapter of life without having completed advance care planning; others will have diligently expressed their treatment preferences and designated a surrogate decision-maker whom they trust. It is too late for those who lack decisional capacity to complete an instructional directive (also known as a living will) or to legally designate a proxy/agent/DPOAHC. In such a case, a POLST Paradigm form can benefit patients, even when an Advance Directive cannot. It is not too late for an appointed surrogate decision-maker and a treating physician to complete a POLST form on a patient’s behalf. This allows POLST Paradigm forms to benefit millions of patients so they can avoid burdensome or even harmful treatment that is non-beneficial.

To serve patients who did not plan ahead, some of the rigorous standards designed to ensure that patients’ wishes are authentic (commonly implemented as safeguards when completing Advance Directives), must be given lower priority. The consequence is to lower the standard of proof regarding whether the written expression of patient’s wishes does truly and correctly reflect the patient’s treatment preferences. One example of laxness is that, with few exceptions, POLST Paradigm forms do not require witnesses for the signature of the patient (principal).<sup>21</sup>

As will be discussed, the laxness required to serve some patients may open the door to misrepresentation or even opportunistic abuse of other patients.<sup>22</sup> At worst, those patients who did diligently plan ahead and still

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to award damages that impress malpractice insurance companies and physicians to honor patients’ wishes.

<sup>19</sup> Christopher M. Burkle et al., *Physician perspectives and compliance with patient Advance Directives: the role external factors play on physician decision making*, 13 BMC MED. ETHICS 31 (2012).

<sup>20</sup> STANLEY A. TERMAN, PEACEFUL TRANSITIONS: STORIES OF SUCCESS AND COMPASSION; PLAN NOW, DIE LATER—IRONCLAD STRATEGY 143; 155-162 (2d ed. 2011).

<sup>21</sup> See Charles P. Sabatino & Naomi Karp, *Advanced Illness Care: Evolution of State POLST Programs*, AM. ASS’N OF RETIRED PERSONS PUB. POL’Y INST. 28-35 (2011).

<sup>22</sup> See *infra* Part II(F).

want to receive life-sustaining treatment may instead be greatly harmed, because the physician orders written on their behalf may contribute to their premature death.

POLST Paradigm forms particularly shine in the medical management of the final chapters of patients' lives as they are uniform, consistent, medical order sheets that come with recommendations for reviewing and revising at periodic intervals and when the medical status of patients changes or when patients are transferred. As an illness progresses, the ability to revise orders is thus an asset rather than a liability. Potential problems arise when the forms are expected to reflect patients' final, end-of-life wishes. Even the author has frequently used POLST forms for this purpose, albeit sometimes with modifications, additions, and attachments.

## II. SIX POTENTIAL PROBLEMS WITH POLST FORMS

### A. ONE: POLST forms may not be effective.

The first topic and example illustrate that POLST Paradigm forms may not be effective.<sup>23</sup> Courts can set aside POLST Paradigm forms when there is conflict. In a case detailed below, a physician completed a patient's Medical Orders for Life-Sustaining Treatment (MOLST) form by basing his selected orders on the patient's current condition, in consultation with the patient's son. But the judge relied on a conversation the patient had with a nurse eight years previously about her end-of-life treatment preferences, and especially gave priority to the daughter's statement about her mother's religious views.

In December 2010, in New York State, Judge William P. Polito ruled that a MOLST for 93-year-old Joan Zornow, who suffered from severe dementia, is "a violation of the statutory law, and invalid."<sup>24</sup> Her physician discussed her condition with her son, Douglas, who signed the form that included the order for "No tube feeding." A daughter (one of five other children) brought the case to court. The judge set aside the MOLST based on a conflict he perceived between the physician's order and Mrs. Zornow's Catholic religion. He cited the relevant law, New York State's Family Health Care Decisions Act, which states that "[h]ealth care decisions shall be made on an individualized basis for each patient, and shall be consistent with the values of the patient, including the patient's religious and moral beliefs, to the extent reasonably possible."<sup>25</sup>

Conflicts that escalate to court to debate the fate of a patient who has lost capacity commonly have two components: (1) the presence of family members who disagree and (2) the absence of sufficient documentation

<sup>23</sup> See *infra* Part II(A).

<sup>24</sup> In re Zornow, 919 N.Y.S.2d 273, 275 (N.Y. App. Div. 2010).

<sup>25</sup> N.Y. PUB. HEALTH LAW §§ 2994-d(4)(a)-(b) (McKinney 2011), N.Y. PUB. HEALTH LAW §§ 2994-d(5)(a), (d) (McKinney 2011).

regarding the patient's end-of-life treatment preferences. Judge Polito's explanation of his ruling is interesting in that he concluded that medical orders regarding life-sustaining treatments, "unless particularized... to specific medical conditions actually encountered," are impermissible.<sup>26</sup>

To interpret this statement, suppose Mrs. Zornow did (as the judge implied was necessary) previously "particularize the specific medical conditions actually encountered." She could have documented her wishes as a set of written instructions in a living will. If she had, the case might not have escalated to court. But if the case had still come before Judge Polito, as the presiding judge he may have honored her wishes—even if she had stated her priority was a timely, peaceful death rather than to follow the teaching of her religion. Seen as an instrument to resolve conflict, living wills can thus fulfill two components of the POLST Paradigm vision: to know and to communicate patients' wishes.

Those who are aware of *Zornow* and similar cases have ample reason to conclude that if patients want to be sure that their end-of-life treatment preferences will be honored, they should be advised to complete an Advance Directive and to make sure this form accompanies their POLST.<sup>27</sup> To what extent are patients so informed? Most states merely require clinicians to explain the differences between POLST forms and Advance Directives.<sup>28</sup> To my knowledge no state law, regional guide, or local protocol requires this explanation to include the specific fact that an Advance Directive may resolve such conflicts as faced by the family of Mrs. Zornow—although such disclosure is appropriate to include in a POLST Conversation. Nor to my knowledge do training programs for clinicians who conduct the POLST Conversation recommend actively encouraging patients to complete living wills. Typically, the explanation is limited to stating only that POLST forms are not intended to replace Advance Directives—a weak and inadequate statement that is not likely to prevent a prolonged death as Ms. Zornow experienced. Note the time line: Mrs. Zornow's MOLST was signed in September 2009; the court petition was signed in May 2010; Judge Polito issued his ruling in December 2010; and she died in December 2011. She thus lived for more than two years in an advanced stage of dementia—perhaps having her life prolonged as others forced her to follow the teachings of her religion as they interpreted them... or perhaps feeling fulfilled by being enabled to follow the teachings of her religion.

In practice, clinicians may encourage patients engaged in advance care planning to complete a POLST Paradigm form or an Advance Directive

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<sup>26</sup> In re Zornow, 919 N.Y.S.2d at 453.

<sup>27</sup> See, e.g., Wendland v. Wendland, 28 P.3d 151 (Cal. 2001); Bush v. Schiavo, 885 So.2d 321 (Fla. 2004).

<sup>28</sup> E.g., CAL. PROB. CODE §4780(c) (2000) ("The health care provider, during the process of completing the Physician Orders for Life Sustaining Treatment form, should inform the patient about the difference between an advance health care directive and the Physician Orders for Life Sustaining Treatment form.").

or both. Without enlightened guidance, patients who are not aware that POLST Paradigm forms—by themselves—are not always effective may wonder, “Why do I need both forms?” They may naïvely assume that the ultimate goal of Advance Directives is an actionable set of physician orders, and since POLST forms already accomplish this, why would they need to complete another form? Similarly, patients who have capacity to sign their own POLST forms may not be informed that if their DPOAHC has not legally designated a specific proxy or agent whom they can trust, the surrogate decision-maker whom the physician may later select may not be aware of their wishes. Even if aware, the surrogate may not be a zealous advocate of the patient’s wishes. Even if the surrogate is an informed and strong advocate, they may lack legal standing if selected by the state’s designated hierarchy or the treating physician. Legal standing may be needed to ensure others honor the patient’s wishes.

Consider the following hypothetical example: suppose Mrs. Zornow had completed only a “particularized” living will, which stated her preference to forgo tube feeding if she reached the stage of advanced dementia as described, but she did not complete a proxy directive. Suppose also that she was admitted to a Catholic hospital or skilled nursing facility whose stated policy is to always provide nutrition and hydration. The clinically designated surrogate decision-maker who signed her POLST form may lack legal standing to fire and hire a new physician, and to transfer her to another institution with policies that would allow the patient’s wishes to be honored. In my experience, only an agent who had been granted such authority by a DPOAHC that the patient (principal) signed and was witnessed would have this authority.<sup>29</sup>

### *1. Are POLST forms or the way they are used responsible?*

Yes, but only indirectly because all forms have limitations. Yet there may be an under-appreciation of the importance of traditional Advance Directives in the POLST movement. This is understandable as it is human nature for people to be more enthusiastic about the “new” and less excited about the “old.” Heightened enthusiasm may even lead to ignoring Advance Directives completely. As evidence, note that the state of Oregon, widely regarded as the leader of the POLST Paradigm, has an electronic registry that stores only POLST forms and does not store Advance Directives.<sup>30</sup>

<sup>29</sup> A story in *Peaceful Transitions* illustrates how a patient’s POLST-appointed surrogate decision-maker may be powerless due to lack of legal standing to demand an “Against Medical Advice” discharge from a faith-based institution that refused to remove a feeding tube after a massive stroke—even though the (semi-fictional) patient (in contrast to Mrs. Zornow) had clearly expressed her wish to forgo life-sustaining treatment if she were in her present condition. See Terman, *supra* note 20.

<sup>30</sup> Email from Dr. Terri Schmidt to Dr. Stanley Terman’s office (Jan. 28, 2013). Her answer to, “Can you tell me if the Oregon POLST Registry includes Advance Directives as well?” was: “It does not. POLST only.”

Leaders of the POLST movement may consider it confusing to include in their training modules a strong recommendation to retain the “old.” Their attitude could be supported by the “bad press” living wills have received in recent years.<sup>31</sup> Yet some leading professionals choose to blame the entire class of such forms instead of searching for ways to design an improved form. Improved Advance Directive and living will forms could fulfill an important goal of advance care planning, which simply stated (in words designed for non-professionals) is to provide “a legal form in which you can express your present competent decisions about what treatment you DO or do NOT want, for specific future medical and mental conditions.”<sup>32</sup>

## 2. Recommendations

Consider three recommendations to make POLST Paradigm forms effective: (1) patients should be encouraged to complete a living will that is clear and specific (“particularized”); (2) the Advance Directive should legally designate and empower a trusted individual to be the proxy/agent/DPOAHC “to make sure others will honor the patient’s wishes”;<sup>33</sup> and (3) the Advance Directive should be both attached to the POLST form and stored in the electronic POLST registry.

POLST forms should encourage clinicians to consider Advance Directives. The New Jersey POLST form has such an introductory statement: “This Medical Order Sheet is based on the current medical condition of the person referenced below, and their wishes stated verbally or in a written advance directive.”<sup>34</sup> Minnesota’s POLST form uses similar language: “POLST translates an advance directive into provider orders.”<sup>35</sup> Unfortunately, California’s POLST has a far more common statement: “This is a Physician Order Sheet based on the person’s current medical condition and wishes.” Note that the words “written advance directive” are more specific than the word “wishes.”<sup>36</sup> Also, California’s statement is ambiguous, and if one interprets the word “current” as modifying the word “wishes,”

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<sup>31</sup> See Angela Fagerlin & Carl E. Schneider, *Enough: The Failure of the Living Will*, 34 HASTINGS CTR. REP. 30 (2004).

<sup>32</sup> Stanley A. Terman, *The “Dementia Fear”: What do you already KNOW about it? How would you PLAN for it?* (2013), available at <https://www.surveymonkey.com/s/Dementia-Fear>.

<sup>33</sup> The words in quotes reflect the “contract” style of an agent’s job description: to serve as the patient’s advocate based on the patient’s previously written known wishes. In contrast, the agent does *not* serve to make decisions based on substituted judgment, as long as the patient’s specific treatment preference for the specific condition is clearly known.

<sup>34</sup> STATE OF NEW JERSEY DEP’T OF HEALTH, <http://www.state.nj.us/health/advancedirective/polst.shtml> (last visited June 28, 2013).

<sup>35</sup> See e.g., Minnesota POLST form (as endorsed by the MINN. MED. ASS’N BD. OF TRUSTEES and the MINN. EMERGENCY MED. SERVS. REGULATORY BD.), <http://www.mnmed.org/Portals/mma/PDFs/POLSTform.pdf> (last visited July 5, 2013).

<sup>36</sup> See California POLST form, *supra* note 8.

then physicians are not encouraged to consider the patient's *past* wishes as expressed in their Advance Directives.

One state, Washington, changed its introductory statement from embracing, to ignoring Advance Directives. The July 2000 Washington form stated: "This is a Physician Order Sheet. Based on patient/resident wishes and medical indicates, it summarizes any Advance Directive." The February 2011 form states: "...set of medical orders intended to guide emergency medical treatment for persons with advanced life limiting illness based on their current medical condition and goals." Again, if "current" modifies "goals" there is no suggestion to consider Advance Directives completed in the past.

Clinicians and patients could be educated to improve the quality of informed consent. Patients could be asked if they have specific treatment preferences for specific end-of-life conditions such as total paralysis, locked-in state, permanent coma, or an advanced stage of dementia. Note that merely citing the "stage" of dementia is vague and could therefore lead to conflict regarding precisely when to implement the wishes in a patient's living will. Yet a living will can specifically describe the future condition, even though the course of dementia is variable and people differ with respect to which symptoms, losses of function, unwanted behaviors, and conflicts with lifelong values they consider determinative. One advance care planning tool that strives for such specificity is the "Natural Dying—Living Will."<sup>37</sup>

How might such recommendations have worked for Mrs. Zornow? The clinician who conducted the POLST Conversation with her, while she still had capacity, or who helped her complete her living will, could take into consideration that A) she was Catholic, and B) the New York Family Health Care Decision Act prioritizes religion.<sup>38</sup> So Mrs. Zornow could have been presented two options and asked to decide between them:

[ ] *Initial here if this is what you want:*

"If I reach an advanced stage of dementia (as detailed in my living will), then I DO want to receive tube feeding indefinitely, since I am Catholic."

[ ] *Initial here if this is what you want:*

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<sup>37</sup> *Natural Dying Living Will Cards*, CARING ADVOCATES, <http://www.caringadvocates.org/MyWayCards/index.php> (last visited May 14, 2013).

<sup>38</sup> N.Y. PUB. HEALTH LAW §§ 2994-d (McKinney 2011). "Health care agents are required to make decisions according to the patient's wishes, including the patient's religious and moral beliefs" including "whether the strength and durability of the patient's religious and moral beliefs make a more recent change of heart unlikely." *Frequently Asked Questions*, NEW YORK STATE DEP'T OF HEALTH, [http://www.health.ny.gov/professionals/patients/patient\\_rights/molst/frequently\\_asked\\_questions.htm](http://www.health.ny.gov/professionals/patients/patient_rights/molst/frequently_asked_questions.htm) (last visited May 14, 2013).

“If I reach an advanced stage of dementia (as detailed in my living will), then I DO NOT want to receive tube feeding, even though I am Catholic.”

In sum, memorializing this decision may have saved the Zornow family from conflict—if she had selected the first option; or saved Mrs. Zornow from prolonged suffering as litigation proceeded slowly—if she had selected the second option.

***B. TWO: Using POLST forms may not be moral.***

Several Catholic theologians and clinicians have criticized POLST Paradigm forms for being immoral. E. Christian Brugger stated that POLST forms allow patients to refuse any treatment for any reason at any time.<sup>39</sup> He further characterized the act of physicians’ completion of POLST forms as a step toward legitimizing the practice of physician-assisted suicide.<sup>40</sup>

A group of Wisconsin Bishops broadly criticized the use of POLST Paradigm forms.<sup>41</sup> They wrote:

It is difficult to determine in advance whether specific medical treatments, from an ethical perspective, are absolutely necessary or optional. These decisions depend upon factors such as the benefits, expected outcomes, and the risks or burdens of the treatment. A POLST oversimplifies these decisions and bears the real risk that an indication may be made on it to withhold a treatment that, in particular circumstances, might be an act of euthanasia. Despite the possible benefits of these documents, this risk is too grave to be acceptable.<sup>42</sup>

The Wisconsin Bishops had “concerns as to whether [a POLST form] accurately reflects and protects a person’s wishes.”<sup>43</sup> They noted “the lack of a patient signature acknowledging that the form truly represents a person’s choices” and the “potential conflict with other advance care directives,”<sup>44</sup>

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<sup>39</sup> E. Christian Brugger, *A Critique of the National POLST Paradigm through an Analysis of Colorado’s New MOST Legislation*, 78:2 LINACRE QUARTERLY 157 (2011); E. Christian Brugger, Stephen Pavela, William Toffler & Franklin Smith, *POLST and Catholic Health Care: Are The Two Compatible?* 37 ETHICS & MEDICS 1 (2012).

<sup>40</sup> Brugger et al., *supra* note 39, at 1.

<sup>41</sup> Catholic Bishops of Wisconsin, *Upholding the Dignity of Human Life: A Pastoral Statement on Physician Orders for Life-Sustaining Treatment (POLST) from the Catholic Bishops of Wisconsin* (2012), available at [www.wisconsinatholic.org/WCC%20Upholding%20Dignity%20POLST%20Statement%20FINAL%207-23.pdf](http://www.wisconsinatholic.org/WCC%20Upholding%20Dignity%20POLST%20Statement%20FINAL%207-23.pdf).

<sup>42</sup> *Id.*

<sup>43</sup> *Id.*

<sup>44</sup> *Id.*

both of which are considered herein. “Due to the serious and real threats to the dignity of human life,” the Bishops “encouraged all Catholics to avoid using all such documents, programs, and materials.”<sup>45</sup>

Before discussing the Bishops’ criticisms of POLST, consider their religious point of view. It is immoral for a person to intentionally plan in advance for his or her death,<sup>46</sup> and it is immoral to direct others to carry out their treatment instructions if the intent is to hasten dying.<sup>47</sup> This religious viewpoint contrasts with patients’ (secular) legal rights. The U.S. Supreme Court embraced the right of competent adult patients to refuse any intrusive treatment, even if such refusal may hasten their dying.<sup>48</sup>

One area of controversy is whether the right to refuse applies only to “medical treatment” but not to what some people insist is “basic care.” Most clinicians now view tube feeding as medical treatment, however assisted oral feeding is more controversial. Consider an oral comment of then-U.S. Supreme Court Justice William Rehnquist. First, he listened to an argument regarding why it is appropriate to force-feed a prisoner on a hunger strike to prevent him from killing himself, but not appropriate to force-feed medically sick patients who indicated they wish to forgo nutrition and hydration. Then he said: “[i]t seems odd that your bodily integrity is violated by sticking a needle in your arm, but not by sticking a spoon in your mouth. I mean... how would you force-feed these people in a way that would not violate their bodily integrity?”<sup>49</sup>

Regarding the Bishops’ criticism, consider (as noted above) that some “immediately actionable” orders on POLST Paradigm forms are actually implemented contingently, when the patient’s condition changes.<sup>50</sup> This example is relevant: POLST forms must be completed when the patient’s heart and lungs are still functioning. The forms tell emergency personnel what to do in the future—IF the patient’s heart stops. It is noteworthy that Judge Polito did not rescind Mrs. Zornow’s DNR order.

Is there an inherent clinical or moral difference between cardio-pulmonary resuscitation and assisted feeding—in terms of how beneficial versus how invasive the two techniques are? Or is it just that our society has had many more years to get used to forgoing CPR than assisted feeding? Or does CPR seem more medical than assisted feeding? Whatever the reason for

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<sup>45</sup> *Id.*

<sup>46</sup> *Id.*

<sup>47</sup> Catholic Bishops of Wisconsin, *supra* note 41.

<sup>48</sup> *Cruzan v. Director*, 497 U.S. 261, 280 (1990).

<sup>49</sup> Argument of Dennis C. Vacco, *Oyez*, available at [http://www.oyez.org/cases/1990-1999/1996/1996\\_95\\_1858/argument](http://www.oyez.org/cases/1990-1999/1996/1996_95_1858/argument).

<sup>50</sup> See *supra* note 8 and accompanying text (stating that POLST forms create immediately actionable orders for future contingencies).

the discrepancy, the ability to exercise a personal right seems to depend on what kind of invasive treatment is being considered.<sup>51</sup>

Would the Bishops consider it moral for a physician to withhold or withdraw life-sustaining treatment—if the physician judges that, based on the patient’s current, condition, she cannot benefit from life-sustaining treatments that are likely to cause her significant burden or harm? One may doubt the Bishops meant to state it is *never* moral to write orders to forgo life-sustaining treatment for suffering patients. More likely, they would state such orders *can sometimes* be immoral and would be, if the treatment refused is neither extraordinary nor disproportionate.

One example of patients for whom treatment refusal is *immoral* is likely patients whose only source of current suffering is anticipatory anxiety due to the “Dementia Fear.” This is the realistic fear that after patients reach an advanced stage of dementia, others who mean well will force patients to endure a prolonged dying with suffering as they impose huge emotional, physical, and financial burdens on their loved ones (whom they will then not be able to recognize). Even if their loved ones did want to relieve their suffering, they fear becoming “stuck” because in advanced dementia there is often “no plug to pull.” Thus, they seek a plan to die sooner so they never reach an advanced stage of dementia. To facilitate their plan, physicians could check the box for “Comfort Measures Only” on POLST forms. This would set the stage for earlier dying.

Such an order is unnecessary and therefore tragic: Unnecessary since POLST Paradigm forms *could* present patients the option to refuse “help from another person’s hand to put food and fluid in their mouth”—after they reach an advanced stage of dementia. Tragic because patients who are not aware that one option is to stop such “help” may wrongly believe it is urgent for them to die while they still can—instead of later when they would prefer, and would have died, if a health care professional had informed them about this alternative. In this sense, being inadequately informed can result in premature dying.

Those who worry about the “slippery slope” have more reason due to at least one recent event. In March 2013, the Swiss facility Dignitas provided Physician-Assisted Dying for a patient who had capacity but whose only medical issue was early stage dementia.<sup>52</sup> Based on his life expectancy and the typical course of dementia, his premature dying probably sacrificed two to three years of life. Even if his cognitive functioning was objectively impaired, he may still have had the potential to enjoy life and his loved ones may also have enjoyed him. Philosophically and clinically, neither the patient himself nor his physician might have been able to accurately predict

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<sup>51</sup> See also Thaddeus M. Pope & Lindsey E. Anderson, *Voluntarily Stopping Eating and Drinking: A Legal Treatment Option at the End of Life*, 17 WIDENER L. REV. 363 (2011).

<sup>52</sup> Clare Dyer, *Dignitas accepts the first case of suicide for dementia from the UK*, 346 BRITISH MED. J. f3595 (Jun. 3, 2013).

the patient's then perceived quality of life—if he had lived to reach middle stage dementia.<sup>53</sup>

### ***1. Are POLST forms or the way they are used responsible?***

Consider three questions: Are POLST Paradigm forms inherently immoral? Do POLST Paradigm forms make it easier for patients and physicians to act immorally? Do the forms allow this to happen more often?

Ron Hamel opined that POLST forms are not inherently immoral.<sup>54</sup> They are merely a set of standardized physician orders that may or may not be moral, depending on the basis for writing the specific orders. Physicians can of course use forms other than the POLST to write orders to hasten dying. In some venues, such orders are routine. For example, in the Intensive Care Unit setting, as many as 70% of patients die after the physician and family member agree to withdraw or to withhold life-sustaining treatment.<sup>55</sup> On the other hand, POLST Paradigm forms do make it easier for any patient to forgo all life-sustaining treatment to hasten death by merely checking the appropriate box to implement an immediately actionable physician order that other clinicians are required to honor. Furthermore, since these orders can be implemented without witnessing the patients' signature, it is easier to write such an order against patients' true wishes. As will be discussed, this makes it possible for surrogate decision-makers to use POLST forms to hasten the dying of patients who really want to live, which almost all people regard as wrong. To my knowledge, no data are available regarding whether dying is hastened more frequently because POLST forms make it easier to write such orders.

### ***2. Recommendation***

POLST Paradigm forms could require physicians to attest to this moral statement after they evaluate the patient, as they sign the completed form: "My orders to withhold or withdraw life-sustaining treatment are based on the patient's current condition, which has reached a point where in my opinion, the harms and burdens of treatment outweigh the possible benefits

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<sup>53</sup> Calculations and references available from this article's author on request.

<sup>54</sup> Ron Hamel, *POLST Under Fire*, 20 HEALTH CARE ETHICS USA 30 (2012). Ron Hamel is Senior Director, Ethics, at Catholic Health Ass'n (CHA) and Editor of the quarterly newsletter HEALTH CARE ETHICS USA, jointly published by the Ctr. for Health Care Ethics at Saint Louis Univ. and the CHA.

<sup>55</sup> See D. A. Asch, J. Hansen-Flaschen & P. N. Lancken, *Decisions to limit or continue life-sustaining treatment by critical care physicians in the United States: conflicts between physicians' practices and patients' wishes*, 151 AM. J. RESPIR. CRIT. CARE MED. 288 (1995); D. J. C. Wilkinson & J. Savulescu, *Knowing when to stop: futility in the intensive care unit*, 24 CURR OPIN ANAESTHESIOL. 160 (2011); N. Collins, D. Phelan & E. Carton, *End of life in ICU--care of the dying or 'pulling the plug'?*, 99 IRISH MED J. 112 (2006).

of treatment.” This recommendation prompts several questions, explored below.

*a. Should physicians be responsible for monitoring treatment decisions made by patients (or on behalf of patients)?*

Yes. According to many state laws, physicians are not obligated to comply with any patient treatment request or treatment refusal if, in their opinion, the treatment would be medically ineffective or non-beneficial; thus they are implicitly required to determine if medical treatment is or is not effective and beneficial. Physicians are similarly not obligated to comply if treatment is contrary to generally accepted health care standards or if the treatment conflicts with the physician’s personal moral conscience.<sup>56</sup>

*b. Should secular physicians monitor the morality of their patients’ treatment decisions, especially those based on principles of Catholic bioethics?*

Yes. While some consider the Catholic religion to be conservative, its bioethics has a long history of secular acceptance of certain principles. This example is relevant: the Unified Health-Care Decision Act embodied a secular version of the principle of proportionality since the form was first published in 1994. This form phrases one end-of-life option as: “I do not want my life to be prolonged if. . . (iii) the likely risks and burdens of treatment would outweigh the expected benefits.”<sup>57</sup> Additionally, physicians who sign patients’ forms as part of the process of (advance) informed consent are professionally obligated to verify that their patients have not lost capacity and are not affected by impaired judgment. For decisions that may lead to premature dying, there is considerable overlap between what religious leaders consider immoral and what clinicians consider poor judgment.

*c. Can a physician attestation overcome the objections of the Bishops and other Catholic leaders?*

Possibly, because if the physician’s moral statement were true and correct, then (to again paraphrase Brugger) patients would no longer be able to refuse any treatment for any reason at any time (and thus commit the immoral act of Physician-Assisted Dying).

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<sup>56</sup> CAL. PROB. CODE §§ 4734-4735 (West 2013).

<sup>57</sup> *Health-Care Decisions Act*, UNIFORM LAW COMM’N, [http://www.uniformlaws.org/Act.aspx?title=Health-Care Decisions Act](http://www.uniformlaws.org/Act.aspx?title=Health-Care%20Decisions%20Act). This conditional living will instruction appears in the recommended forms of many states and other institutions. *E.g.*, CALIFORNIA HOSPITAL ASS’N, Advance Health Care Directive Form 3.1 (2012), available at <http://www.calhospital.org/resource/advance-health-care-directive> (last accessed May 14, 2013).

In sum, the recommended additional physician statement is designed to fulfill criteria of the principle of proportionality as set forth by Pope Pius XII, which focuses on treatment based on the patient's *current* condition.<sup>58</sup> Some may still argue whether or not a specific treatment is extraordinary and disproportionate for certain diagnoses such as the Permanent Vegetative State. Yet following this recommendation may comfort many even if it cannot change the minds of all.

***C. THREE: POLST forms may not reflect patients' authentic wishes.***

After considering this potential problem in general, two important examples of treatment decisions are discussed in detail. One is an order that most POLST Paradigm forms mandate, but which some patients may not want; the other is an order that patients may want but all POLST forms omit.

The POLST vision strives to ensure that seriously ill persons' wishes regarding life-sustaining treatments are known. This is the foundation of all that follows, but almost no data are available to determine if this goal is being attained. In the single, small pilot study on point, Meyers *et al.* (2004) asked the right question: "What are your end-of-life wishes?" Unfortunately the study included very few patients. They compared the wishes elicited in 7 interviews (2 residents and 5 surrogates) to their POLST forms. The POLST forms indicated a higher level of medical intervention than the patients actually desired in 2 of the 7 cases.<sup>59</sup> Hickman *et al.* referred to Meyers' article more recently as they also admitted "[a]dditional data are needed to confirm that the orders on the POLST are reflective of resident treatment preferences."<sup>60</sup> To date, we have virtually no proof that the items checked on POLST forms do accurately reflect what patients or their surrogate decision-makers say are their true treatment preferences.

***1. POLST forms may mandate a treatment that some patients do not want.***

The initial impetus for POLST Paradigm forms, like living wills, were ICU patients and others who required high-tech interventions. Overlooked were people who had dementia. Today, dementia is the fifth

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<sup>58</sup> Pope Pius XII, *The Prolongation of Life: Allocution to the International Congress of Anesthesiologists*, in 4 THE POPE SPEAKS 395 (1958). See also Stanley A. Terman, *Is the Principle of Proportionality Sufficient to Guide Physicians' Decisions Regarding Withholding/Withdrawing Life-Sustaining Treatment After Suicide Attempts?* 13 AM. J. OF BIOETHICS 22 (2013).

<sup>59</sup> J. L. Meyers, C. Moore, A. McGrory, J. Sparr & M. Ahern, *Physician orders for life-sustaining treatment form: honoring end-of-life directives for nursing home residents*, 30 J. GERONTOL NURS. 37 (2004).

<sup>60</sup> S. E. Hickman et al., *The consistency between treatments provided to nursing facility residents and orders on the physician orders for life-sustaining treatment form*, 59 J. AM. GERIATRICS SOC'Y 2091 (2011).

leading cause of death for people over the age of 65. By mid-century, the number of dementia patients is expected to increase three-fold.

Why do people want to avoid prolonged dying in the terminal, advanced stage of dementia? Common reasons include the following: they do not want to be totally dependent on others for care as they endure a prolonged dying with suffering. They do not want to burden others whom they can no longer recognize. They do not want to be remembered as they lived in a state they consider “indignity.” Less common but important: advanced dementia patients may experience pain and suffering that caring physicians fail to recognize and thus under-treat (or do not treat at all), because patients who no longer can communicate often act in ways that are not typical for other patients who are in pain.

To avoid prolonged dying, some patients want to forgo a certain kind of assistance: help from another person’s hand to put food and fluid in their mouth after they have become dependent on such help. But most current POLST forms seem to mandate the opposite. Minnesota, for example, includes this order on its POLST form: “Oral fluids and nutrition *must always* be offered if medically feasible.” About two-thirds of POLST Paradigm forms use either the word “must” or “always.”

Check boxes accompany all choices on POLST forms—except for oral feeding. Minnesota is the only state that does provide a check box; however its POLST form is printed with this box *already checked*—to prevent patients from making any other choice. Three states (New Jersey,<sup>61</sup> California,<sup>62</sup> and Hawaii<sup>63</sup>) have orders that soften the “mandate” by including the words “and desired.” But no POLST provides a box that physicians can check. And no POLST form offers any other standard option that physicians can order.

Why is a check box so important? Because it signals to each patient that it is possible to discuss this treatment option with their physician or the clinician who conducts the POLST Conversation, and then make a decision regarding this life-sustaining treatment—which decision could determine *how much and how long the patient must suffer before dying*.

Loved ones, caregivers, and providers may make a culturally based assumption that reflects the bias of our food-loving society: “Food is love.” Others may naïvely assume that what is correct for feeding-dependent infants is also correct for feeding-dependent terminally ill patients who suffer from dementia. The needs of the dying are different than the needs of infants. Most terminally ill patients prioritize a peaceful and timely dying. Dying from a total fast can be comfortable. The cause of death is medical

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<sup>61</sup> See New Jersey POLST Form, *supra* note 34.

<sup>62</sup> See 2011 California POLST Form Section C, POLST CALIFORNIA, available at [http://www.capolst.org/documents/CAPOLSTform2011v13web\\_005.pdf](http://www.capolst.org/documents/CAPOLSTform2011v13web_005.pdf).

<sup>63</sup> See Hawaii POLST Form, available at [http://hawaii.gov/health/family-child-health/ems/pdf/Hawaii\\_POLST\\_Form.pdf](http://hawaii.gov/health/family-child-health/ems/pdf/Hawaii_POLST_Form.pdf) (August 2009) (last visited June 28, 2013).

dehydration, not starvation. The alternative, called “comfort feeding only,”<sup>64</sup> may “comfort” others by giving them permission to accept the small amount of food patients can take in and absorb. However the patients may suffer longer and more intensely as they slowly die from starvation and as their intake of even a few calories blocks the metabolic process of ketosis, which reduces hunger and provides a mild euphoria. Patients who do fast from all food and fluid typically die within two weeks. How do we know dying is peaceful? Evidence comes from self-reports of alert patients, from nurses’ observations,<sup>65</sup> from published reports, from clinical experience.<sup>66</sup> If they could speak for themselves, some feeding-dependent patients would say, “Just because I can swallow does not mean I want to swallow!” Caregivers may observe the patient open her mouth when a spoon touches the patient’s cheek or lips; they may then observe her swallow when thickened puree is placed on the very back of her tongue. Some authorities label such “help” as “basic care to which every human being is entitled.” Yet the patient has lost decisional capacity; therefore opening her mouth cannot be considered voluntary or willful. Also, her act of swallowing may be pure reflex. Due to her loss of capacity, the patient cannot appreciate that continuing to receive assisted feeding may only prolong her dying and increase the intensity of her suffering.

This distinction is important: while “help” is withdrawn, food and fluid are not withheld; they are still offered, as they can always be placed in front of the patient. These details of forgoing “help” can be presented to competent patients during a POLST Conversation. Some patients have living wills in which they previously chose this option. In both cases, the POLST form should reflect the patient’s choice. To do so using current POLST Paradigm forms requires physicians to take two actions: (1) cross out the mandated order and (2) handwrite in the opposite. This pragmatic question must then be answered: will physicians actually do this?<sup>67</sup> (If not, then these important patients’ wishes will not be honored.)

For patients whose treatment preferences are not known, the “best interest” ethical standard is often used. Someday it may be possible to put this clinical decision—whether or not to continue help from another person’s hand to put food and fluid in a patient’s mouth—on firm ground. A survey could inform patients what it is like to live in an advanced stage of dementia

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<sup>64</sup> Eric J. Palecek et al., *Comfort feeding only: a proposal to bring clarity to decision-making regarding difficulty with eating for persons with advanced dementia*, 58 J. AM. GERIATRICS SOC’Y 580 (2010).

<sup>65</sup> Linda Ganzini et al., *Nurses’ Experiences with Hospice Patients Who Refuse Food and Fluids to Hasten Death*, 349 N. ENGL. J. MED. 359 (2003); H. R. Pasman et al., *Discomfort in Nursing Home Patients With Severe Dementia in Whom Artificial Nutrition and Hydration Is Forgone*, 165 ARCH. INTERN. MED. 1729 (2005).

<sup>66</sup> This article’s author has also fasted twice to learn from the experience.

<sup>67</sup> Survey research is in progress to begin answering this question. *Attitudes of Professionals Regarding the “Dementia Fear.”* <https://www.surveymonkey.com/s/ProsReDementiaFear>.

and then ask: “Would you want this kind of help to continue for as long as it is medically feasible?” If a statistically adequate number of people who were not subject to selection bias responded, the data may support the often-used “reasonable person” basis for making clinical decisions.<sup>68</sup> Until such data are available, patients must competently indicate this preference *in advance*; that is, by memorializing their decision in a personal living will.

Currently, POLST forms and the POLST Conversation inform neither patients nor physicians that such a choice is available. This lack of knowledge can lead to the “Dementia Fear” that in turn, may lead to premature dying (as explained above).<sup>69</sup>

*a. Are POLST forms or the way they are used responsible?*

Yes. Those who insist on wording the “mandate” as “always offer oral food if feasible” have a noble goal: to preserve life. But they should consider that withholding information about the alternative from patients who might select this option could lead to the unintended consequence of premature dying (as defined by what the *informed* patient would prefer) due to the “Dementia Fear.”

*b. Recommendations*

POLST Conversations could inform patients that an order could be implemented in the future, after they reach the advanced stage of dementia, which would make premature dying unnecessary. Patients and physicians could choose from this set of three orders, each with its own check box:

If the patient has become dependent on help provided by another person’s hand to put food and fluid in his/her mouth due to severe cognitive impairment (not due to a physical impairment or handicap)... **[Check ONE box below]:**

- A)** Do not provide this help, but always offer food and fluid by placing them in front of the patient; **OR,**  
 **B)** Provide this help for a limited time trial of ( \_\_\_ ) days/weeks/months—when I will re-evaluate the patient and possibly revise my order; **OR,**

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<sup>68</sup> Presently, only the results from a biased sample of patients are available from the non-profit organization, Caring Advocates. The survey is *Learn Before You Decide* at <http://caringadvocates.org/learn-before-you-decide/index.php>. An example of a clinically useful (hypothetical) result: of those surveyed, 95% would not want to prolong their dying in an advanced stage of dementia by receiving help from another person’s hand to put food and fluid in their mouth (after excluding those who follow religions that require life-sustaining treatment unless death is imminent, or if the intervention causes direct harm or cannot provide any benefit).

<sup>69</sup> See *supra* Part II(B).

C) Continue this help for as long as it is medically feasible.

To some, this order will still seem controversial; hence the following requirement could be added to option (A): "...If REFUSED in the patient's Living Will AND by the patient's designated proxy/agent/DPOAHC." As written, the two sources must agree and be consistent so this additional requirement provides a higher standard of proof that this order does truly reflect the patient's wishes than for any other POLST order. This high standard of proof may allow physicians to feel comfortable as they sign to attest that "these orders are consistent with the person's preferences."

## **2. POLST forms may omit offering a treatment that some patients do want.**

Patients for whom POLST forms are completed generally are expected to live less than twelve months.<sup>70</sup> In the last weeks of life, between 5% and 35% of patients receiving palliative care in hospice programs experience severe pain and other intractable symptoms.<sup>71</sup> For such patients, Palliative Sedation to Unconsciousness may be the only means to provide them relief. The American Medical Association's Council on Ethical and Judicial Affairs published a "recommended ethical guideline." It stated, "... (3) Physicians should ensure that the patient and/or the patient's surrogate have given informed consent for Palliative Sedation to Unconsciousness."<sup>72</sup> While POLST forms ask for either the patient or her surrogate decision-maker to sign (that is, to give consent) for the entire set of orders, such forms do not ask for informed consent for any specific treatment such as Palliative Sedation to Unconsciousness... for a specific situation, such as unending, unbearable pain and suffering that cannot be relieved by any other means.

While some may argue that the wording on POLST Paradigm forms is already adequate—for example, "Use aggressive comfort treatment to relieve pain and suffering by using any medication by any route, positioning, wound care and other measures" (New Jersey)<sup>73</sup>—there are three reasons why POLST forms should routinely ask for specific informed consent for Palliative Sedation to Unconsciousness. First, it would fulfill the ethical

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<sup>70</sup> See *POLST Forms and Instructions*, CEDARS-SINAI, available at <http://www.cedars-sinai.edu/Patients/Programs-and-Services/Healthcare-Ethics-POLST-Forms--Instructions.aspx> ("A POLST should be strongly considered for any patient for whom death in the next 12 months would not be surprising.")

<sup>71</sup> T. E. Quill, I. R. Byock, *Responding to intractable terminal suffering: the role of terminal sedation and voluntary refusal of food and fluids*, 132 ANN INTERN MED. 408 (2000).

<sup>72</sup> AM. MED. ASS'N COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS, *Sedation to Unconsciousness in End-of-Life Care* 6 (2008).

<sup>73</sup> See *Sedation to Unconsciousness in End-of-Life Care*, *supra* note 72. Author's Note: using the word "aggressive" is rare.

standard as recommended by the American Medical Association (above).<sup>74</sup> Second, it would ensure that patients were informed about Palliative Sedation to Unconsciousness. This is important since failure to inform could lead to patients' unnecessary suffering and possibly to lawsuits based on not adequately informing patients.<sup>75</sup> Third, it would allow patients to "shop" for a willing physician before a possible crisis of pain and thus find a physician who is willing to provide this type of care. Why might this be necessary? Because a 2007 poll showed that about one out of six physicians object to "Terminal Sedation" because of a perceived conflict with their moral conscience or religious beliefs.<sup>76</sup>

*a. Are POLST forms or the way they are used responsible?*

Yes, POLST forms (or members of the Task Force who revised or created the forms) may be responsible for not explicitly informing patients about a treatment that they would wish to discuss for the purpose of deciding if they prefer it. As POLST forms are completed in practice, it is rare for patients to request, for physicians to recommend, or for other clinicians to discuss this option during POLST Conversations.

*b. Recommendation*

The POLST form could include a space for physicians to sign to indicate that their patient gave informed consent to Palliative Sedation to Unconsciousness. Physicians who sign would thereby be expressing their willingness to provide this kind of treatment, when and if necessary. Even if the particular physician who signed the POLST form is not available when a crescendo of pain and suffering occurs, patients who previously gave their consent will have laid the ground work to make it easier for their surrogate decision-makers to then find a physician who is willing to provide the necessary order to relieve their pain.

In sum, in my clinical experience, the two greatest end-of-life fears are being forced to endure: (1) months to years in an advanced stage of dementia and (2) days to weeks of unending, unbearable pain and suffering. POLST Paradigm forms could eliminate anxiety about these fears by presenting treatment options that patients can discuss in a POLST Conversation. Patients can then decide if they want to select these options. If they do, the POLST form could be designed with appropriate check boxes and spaces to give consent so that physicians can easily and routinely

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<sup>74</sup> See *id.* and accompanying text (discussing the American Medical Association's recommended ethical guideline for Palliative Sedation to Unconsciousness).

<sup>75</sup> See, e.g., *Hargett v. VITAS Healthcare Corp.*, No. RG10547255 (Alameda Cnty. Sup. Ct. 2010).

<sup>76</sup> Farr A. Curlin et al., *Religion, conscience, and controversial clinical practices*, 356 NEW ENG. J. MED. 593, 596 (2007).

implement these orders which have the potential to reduce their patient's future end-of-life suffering.

***D. FOUR: POLST forms may not be durable. Conflicts with Advance Directives may be resolved in ways that are not consistent with constitutional rights or state laws.***

The POLST Paradigm vision strives to ensure that a seriously ill person's wishes are honored across all health care settings. There are two ways a person's wishes may not be honored. First, physicians may place a higher priority on treating patients' current condition than on honoring patients' previously expressed wishes. Second, if there is a conflict, the POLST law or community standard of practice may place a higher priority on the physicians' orders on the POLST form than on patients' previously expressed wishes.

As long as patients have capacity, they can discuss their wishes with their physician, review their own POLST form to make sure their wishes are faithfully reflected therein, and demand changes as needed. But after patients lose capacity to make treatment decisions, the balance of power shifts significantly to physicians. In California, patients with capacity can revoke a POLST; in contrast, patients who have lost capacity depend on a "legally recognized decision-maker" whose authority is limited in that he or she cannot revoke but can only "request to modify the orders." Some states allow a DPOAHC designated in a valid Advance Directive to revoke POLST forms.

POLST forms are designed to be reviewed both periodically and when the patient's condition changes. Note the emphasis on considering patients' current condition in California law: "[a] physician may conduct an evaluation of the individual and, if possible, in consultation with the individual, or the individual's legally recognized health care decision-maker, issue a new order consistent with the most current information available about the individual's health status and goals of care."<sup>77</sup> While all negative results are tentative, I have identified no comparably strong statement that encourages physicians to faithfully honor their patients' Advance Directives. Instead, I found the opposite: a box that physicians could easily check, stating "Advance Directive not available." The California POLST lacked any suggestion to make a "best effort" or even a "reasonable attempt" to obtain and review a patient's Advance Directive if the physician knew one did exist.

Some states' POLST laws transparently give physicians broad authority to appoint surrogate decision-makers by using the words "or other." Additional words may not change the effect. Consider this category for a "legally recognized decision-maker": the "person whom the patient's physician believes best knows what is in the patient's best interest and will

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<sup>77</sup> CAL. PROB. CODE § 4781.2(c) (West 2013).

make decisions in accordance with the patient's expressed wishes and values to the extent known."<sup>78</sup> Such a person could potentially be the family member who is threatening to sue the physician, is the most demanding, or about whom the physician feels most comfortable (in other words, who is most likely to agree with the physician's orders). Ideally, the person selected should be the one who can best serve as the patient's independent advocate, to make sure others will honor the patient's wishes.

What if there is an inconsistency between the physician's orders on a POLST form and either the patient's expressed wishes in a living will, or the instructions of the patient's proxy/agent? Charles Sabatino and Naomi Karp analyzed twelve states' laws in relation to this question.<sup>79</sup> POLST orders would or might prevail in all states but Tennessee.<sup>80</sup> In Idaho, North Carolina, and Utah, the POLST always prevails.<sup>81</sup> In New York and West Virginia, clinicians are instructed to apply the "best interest" standard.<sup>82</sup> Hawaii, Minnesota, Oregon, and Vermont had not provided relevant guidelines to resolve this issue, as of April 2011.<sup>83</sup>

In California and Washington, the most recently signed form will prevail.<sup>84</sup> In practice, the POLST form will almost always prevail after patients lose capacity because the POLST is the only form that can be updated "...appropriately to resolve any conflicts."<sup>85</sup> Yet the Constitution protects patients' right to refuse unwanted medical treatment, and the Patient Self-Determination Act informs patients that they may make such health care decisions *in advance* via their state's law regarding Advance Directives.<sup>86</sup> A court case may be necessary to determine if "the most recently signed form will prevail" is constitutional and otherwise consistent with federal and state law. If not, legislators will need to change the law.

States may be less than transparent regarding which form will prevail. One cannot learn that the most recently signed form will prevail from the example Advance Directive in California Probate Code Section 4701 or from Side 2 of the POLST form.<sup>87</sup> Other than Probate Code Section

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<sup>78</sup> See California POLST Form, *supra* note 8 at Side 2, "Completing POLST" (Apr. 1, 2011 version).

<sup>79</sup> Sabatino & Karp, *supra* note 21 at 8.

<sup>80</sup> *Id.* at 12.

<sup>81</sup> *Id.*

<sup>82</sup> *Id.*

<sup>83</sup> *Id.*

<sup>84</sup> *Id.*

<sup>85</sup> 2011 California POLST Form Directions for Health Care Provider, POLST CALIFORNIA, available at [http://www.capolst.org/documents/CAPOLSTform2011v13web\\_005.pdf](http://www.capolst.org/documents/CAPOLSTform2011v13web_005.pdf) (last visited June 29, 2013).

<sup>86</sup> Patient Self Determination Act of 1990, 42 U.S.C. §1395cc (2011).

<sup>87</sup> POLST CALIFORNIA, [www.caPOLST.org](http://www.caPOLST.org) (last visited May 15, 2013).

4781.4,<sup>88</sup> one must check the Frequently Asked Questions on the California POLST website to obtain this information.<sup>89</sup>

### ***1. Are POLST forms or the way they are used responsible?***

Yes. Ways in which the forms and supporting laws could change are detailed below.

### ***2. Recommendations***

The first set of recommendations is directed at modifying the POLST form and relevant laws. The second set, at what patients can do now.

The introductory statements on POLST forms could indicate that the patient's Advance Directive, if completed, is attached. The box that indicates an Advance Directive is not available could include a statement for the physician to endorse that s/he made his/her best effort (or at least a reasonable attempt) to locate it. The section on "Using POLST" could advise physicians that they may lose immunity if the medical orders they write are not consistent with their patient's wishes, if known. State laws regarding consistency could be changed by adding the words, "the competent patient," so the new law would then read: "In the event of a conflict, the form that *the competent patient* most recently signed will prevail."

What can patients do? They could refuse to sign a POLST form—as recommended by the Bishops of Wisconsin. However this "solution" has two potential problems. After the patient loses capacity, a surrogate decision-maker may sign a POLST on his/her behalf anyway. Also, POLST forms are excellent vehicles to implement consistent instructions regarding medical care across treatment settings, where the patient's changing condition warrants changing physician orders—before the patient reaches an advanced or terminal stage of an illness, when his or her specific requests in a living will apply.

Consider two related recommendations to ensure that instructions in patients' living wills will be considered durable. Patients could place this or a similar statement in both their living wills and initial POLST forms:

If there is a conflict after I have lost capacity between the instructions I previously expressed in my living will and the orders on my current POLST form, I want all to honor the instructions in my living will. (My proxy/agent's role is not to provide Substituted Judgment but to make sure others DO honor my specific wishes—if they are clear and apply to my

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<sup>88</sup> [http://leginfo.legislature.ca.gov/faces/billNavClient.xhtml?bill\\_id=200720080AB3000](http://leginfo.legislature.ca.gov/faces/billNavClient.xhtml?bill_id=200720080AB3000)

<sup>89</sup> *POLST Frequently Asked Questions*, POLST CALIFORNIA, available at <http://www.capolst.org/?for=patients#ten>.

current condition.)<sup>90</sup> I want my future physicians to write medical orders that are consistent with the instructions I expressed in my living will.<sup>91</sup>

Writing this statement on an initial POLST form has the potential advantage that all subsequent revisions will include a copy of this statement. If so, then it will be better (read: *strategic*) to have had such an initial POLST form with this statement than not to have a POLST form at all.

Patients can also include an advisory statement that warns physicians in their living wills, such as the one below. To my knowledge, such a statement appears only in one living will.<sup>92</sup> It is written in the first person to be consistent with the other requests set forth in the patient's living will:

Physicians should consider... You incur three legal risks if you do write orders that conflict with my living will and its expression of my known wishes are clear and available. The first is criminal: providing treatment without consent is the crime of battery, according to most state constitutions and some state statutes. The second is civil: you may lose immunity to being sued for malpractice, since the defense of acting in good faith will not apply. The third is administrative/disciplinary: a complaint could lead to an action being taken against your license.

In sum, POLST Paradigm forms and the laws and regulations that support them are relatively new so they have not yet been thoroughly tested by case law. This essay argues that these forms and the way they are used should respect patients' constitutional right to self-determination and comply with federal and state laws. According to most state laws, once a patient has expressed his or her instructional directives in a living will, only the patient who still possesses capacity can change them (other than a court of law). The recommendations, above all, strive to accomplish two things: to preserve patients' rights and to remind physicians of their legal obligations.

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<sup>90</sup> Some living wills still authorize the proxy/agent to have "leeway" for certain specific items, however.

<sup>91</sup> Patients who include such a statement are likely to be diligent in keeping their expressed wishes up to date, as long as they have capacity.

<sup>92</sup> *Natural Dying Living Will Cards*, CARING ADVOCATES, <http://www.caringadvocates.org/MyWayCards/index.php> (last visited May 15, 2013).

***E. FIVE: POLST forms may be clinically dangerous.***

Enthusiasm for the POLST Paradigm might lead to overuse of these forms.<sup>93</sup> Some physicians now use POLST forms to document treatment plans for their skilled nursing facility patients; the documents are subsequently placed in the patients' medical charts, for example, instead of using Preferred Intensity of Treatment or Preferred Intensity of Care forms.

Why do physicians prefer POLST forms? Here are some reasons a physician might openly divulge:

- “I am familiar with the POLST form.”
- “The form is convenient and easy to complete.”
- “My patients will need this end-of-life form someday and then it will be easier to revise it.”
- “For any patient who does not strictly qualify to complete the form, I can select ‘Full Treatment.’”
- “It is nice to join the enthusiasm of others in using this new form... therefore, I will use the form with as many patients as possible.”

Here is the potential problem: once a POLST form is posted to a patient's chart, other clinicians may assume the treating physician would not be surprised if the patient died within a year, since this is the most common “mantra” used to determine for which patients POLST forms are appropriate.<sup>94</sup> In reality, where there are applicable laws, the criteria for completing POLST forms are much broader; for example, California Assembly Bill 3000 states that “[a] POLST is particularly useful for individuals who are frail and elderly or who have a compromised medical condition, a prognosis of one year of life, or a terminal illness.”<sup>95</sup> Using the word “or” broadens the qualifying characteristics, as does using vague terms.

Given the recent finding that 78% of physicians misinterpret living wills as DNR orders,<sup>96</sup> the danger of similarly misinterpreting a POLST form should be considered high until proven otherwise. The physician or clinician who carries out the POLST order might not be the same provider who originally wrote the order. This increases the chance that the patient will *not* receive life-sustaining treatment that the patient *actually wants*. Whatever the error rate, the higher the number of patients who have completed POLST

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<sup>93</sup> See Jason W. Manne, *A Critical Look At The Physician Orders For Life-Sustaining Treatment (POLST): What Are Its Weaknesses?* (2007) (unpublished Master's thesis, Univ. of Pittsburgh) (on file with author), available at <http://d-scholarship.pitt.edu/9805/1/Manne-BIOETHICS-ETD1-2007.pdf>.

<sup>94</sup> See *supra* note 70 and accompanying text.

<sup>95</sup> A.B. 3000, 2008 Assemb. (Cal. 2008).

<sup>96</sup> L. Ferdinando & Mirarchi et al., *TRIAD III: Nationwide Assessment of Living Wills and Do Not Resuscitate Orders*, 42 J. EMERG. MED. 511 (2012).

forms, the more patients who will be at risk. Moreover, the least appropriate patients are likely to be those who can live longest and at the highest level of functioning—if they are provided life-sustaining treatment.

On the other hand, it is possible that misinterpretations will be less likely to occur with POLST forms than with pre-hospital DNR orders and especially less than with living wills—precisely because it is easier to train physicians how to interpret a standardized set of orders (POLST) than a diverse set of living wills. Also there is reason to hope for high consistency because physicians are becoming increasingly aware that POLST forms routinely include physician orders for “Full” or for “Limited” treatment, as well as for DNR orders.

Available data do provide insight regarding whether or not physician orders on POLST forms result in consistent treatment.<sup>97</sup> Hickman *et al.* encouragingly wrote, “[o]verall consistency rates between treatments and POLST orders were high for resuscitation (98%).”<sup>98</sup> However a closer look at the numbers reveals lower consistency for the sub-group of patients who did not want life-sustaining treatment. For the 299 patients who did not want CPR, treatment was 100% consistent.<sup>99</sup> Of the 106 who did want “Full Code,” only 12 died and 5 of these had their “Full Code” order revoked. This left only 7 patients to analyze further. To quote Hickman *et al.*: “Resuscitation was not attempted in a majority (86%, 6/7) of the residents with valid ‘Full Code’ orders.” Thus, while consistency was 98% overall, for patients who did want CPR, consistency was only 14%.<sup>100</sup> Personal communication with one of the researchers revealed that treating physicians may have judged CPR as “futile” treatment for most of the patients who received inconsistent treatment (that is, no CPR). Still, if these patients were religious, they may have desired CPR attempts. In such situations, a consultation by an ethics committee is the community standard of practice.

Hickman *et al.* also looked at decisions about tube feeding.<sup>101</sup> For 22 patients, overall treatment was consistent for 14 (a consistency of 63.6%).<sup>102</sup> Three out of 4 whose POLST indicated “no feeding tube” did receive a feeding tube; zero out of 5 who wanted a “defined trial period” received consistent treatment: “all had feeding tubes in place for longer than 30 days, and four of these five residents died with the feeding tube in place.”<sup>103</sup> But all 13 who wanted “long term” tube feeding did consistently receive this treatment.<sup>104</sup> Interestingly, for feeding tube treatment, the errors resulted in the provision of *more* life-sustaining treatment than the patients wanted.

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<sup>97</sup> See S. E. Hickman et al., *supra* note 60.

<sup>98</sup> *Id.*

<sup>99</sup> *Id.*

<sup>100</sup> *Id.*

<sup>101</sup> *Id.*

<sup>102</sup> *Id.*

<sup>103</sup> See S. E. Hickman et al., *supra* note 60.

<sup>104</sup> *Id.*

Regarding antibiotic treatment, all 7 patients who did not want to receive antibiotics still received antibiotics (yielding a consistency of 0%).<sup>105</sup>

One other point can be kept in mind: Hickman *et al.* stated that “[b]ecause of the study methodology, it was difficult to detect undertreatment in the nursing facility. . . .”<sup>106</sup>

### ***1. Are POLST forms or the way they are used responsible?***

This is complicated. While orders on POLST forms may be clear, the basis for selecting appropriate patients is vague and there may be other variables that influence how consistently the orders were carried out. While physicians can write inappropriate orders for patients without using POLST Paradigm forms, the problem created is greater if the forms are overused.

Medicine does not claim to be a perfect science. Still there are several questions that could be asked, including: is it appropriate to compare the numbers Hickman *et al.* observed to the ideal of 100% consistency? Is it appropriate to have lower tolerance for errors where life-sustaining treatment is not provided when wanted, than when it is provided when not wanted (if provision of treatment increases suffering)? Should we be more or less tolerant about errors in CPR than for errors in providing feeding tube treatment or for administering antibiotics? It is beyond the scope of this essay to do more than pose these questions.

Using POLST forms has a great advantage: outcome data are available. Most previous studies are limited. Typically, physicians were given surveys that asked them what they thought they would do in a given situation. In contrast, Hickman *et al.* directly observed what physicians actually did.

What can we learn from the work of Hickman *et al.*? First, there is a problem in lack of consistency for both over-providing and under-providing life-sustaining treatment. While the small numbers do not permit estimating how many patients will be affected on a large scale, patients who want three categories of orders deserve extra attention: (1) those who do want CPR; (2) those who want artificial nutrition and hydration only for a limited time; and (3) those who do not want to receive antibiotics. In general, there is cause for concern because, as mentioned above, the extent of this problem will be determined by both the error rate and the total number of patients at risk. The recommendations below address both.

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<sup>105</sup> Such treatment may not have been clinically “inconsistent” because it may have benefited patients. Some clinicians recommend giving antibiotics for comfort care at the end-of-life. See J. T. Van Der Steen *et al.*, *Discomfort in dementia patients dying from pneumonia and its relief by antibiotics*, 41 SCANDINAVIAN J. OF INFECTIOUS DISEASES 143 (2009).

<sup>106</sup> S. E. Hickman *et al.*, *supra* note 60.

## 2. Recommendations

Lawmakers and policy-makers could make the criteria for completing POLST forms for patients more specific and more appropriately restrictive. They could eliminate such vague terms as “elderly,” “compromised medical condition,” and “frail.”<sup>107</sup>

Physicians who sign POLST orders could be required to attest to this statement above their signatures: “My medical orders are appropriate based on the patient’s probable prognosis.”

Further education of physicians could be directed at improving consistency. Globally, physicians could be made aware of this potential problem. Contrast this example for teaching, as if stated by a patient: “Just because I have a POLST does not mean I want to forgo *any* life-sustaining treatment,” with “Don’t be surprised if I die within a year.”

Following these recommendations may help prevent premature dying for those who are only “elderly” or “frail.” But if the patient has completed an Advance Directive, this last recommendation may be the most compelling: physicians could be alerted/reminded if the law in their state requires them to follow the orders on a POLST form (unless they claim a conflict with conscience) at the same time as physicians are alerted/reminded that the orders they write on POLST forms must be consistent with their patient’s wishes, if known.

In sum, three steps are required: (1) to know, (2) to communicate, and (3) to honor patients’ wishes, so that the execution of the written order is *consistent* with the patient’s true wishes. The overall consistency rate will be the result of multiplying the consistencies for each of three steps. Suppose the accuracy were 90% for each step. Then the overall consistency would be only 73% (.9\*.9\*.9). There are no data regarding the accuracy of the “to know” step except for Meyers *et al.*’s 7 interviews. The accuracy for the “to communicate” step depends on several factors beyond the scope of this essay, but include how diligently the form was completed and how quickly the form could be located. (Obviously the bright color and heavy stock paper that many initially hoped would be adequate were not; this is why electronic POLST registries were started.)

While the numbers in the Hickman *et al.* study are small, what emerges clearly is that errors can be made in both providing and in not providing life-sustaining treatment. Until this important work is repeated and new interventions are shown to improve consistency, it may be appropriate

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<sup>107</sup> Even though the diagnosis of “frailty” is becoming more solid, many physicians and decision-makers may interpret the term “frail” more generally; e.g., as a lay term. In terms of defining appropriate clinical criteria for completing POLST forms, this recommendation to rule-out “frailty” seems too broad for determining which patients qualify for a POLST form: “All persons older than 70 years and all individuals with significant weight loss ( $\geq 5\%$ ) due to chronic disease should be screened for frailty.” See John E. Morley *et al.*, *Frailty Consensus: A Call to Action*, 14 J. AM. MED. DIRS. ASS’N 392 (2013).

to inform patients and surrogate decision-makers that such errors are possible. Thus, one more recommendation is appropriate: advise the proxy/agent/DPOAHC (or appointed surrogate decision-maker) that his or her job description includes making sure that the clinical team does, in fact, carry out the intent of the orders as written on the patient's POLST form.

***F. SIX: POLST forms may open the door to potential abuse.***

POLST forms require the signature of the physician/provider, but do not require a statement that the physician discussed these life-determining orders with the patient.<sup>108</sup> They also generally do not require witnesses.<sup>109</sup> This opens the door to several potential problems, including not obtaining informed consent, providing inadequate information before obtaining consent, and making false (opportunistic) claims that consent was obtained.

In contrast, to complete a valid Advance Directive, witnesses who meet specific qualifications (but not notaries) must attest that the principal's mind was sound and signed voluntarily.<sup>110</sup> Some states have stricter requirements for residents of skilled nursing facilities—in recognition that these patients are more vulnerable to abuse. These are the patients for whom POLST forms are particularly appropriate. Some states require a person who is free of conflict, such as an ombudsman, to sign as one of the witnesses. Relaxing the witnessing requirements opens the door to possible abuse. For example, an heir may wish to inherit more money sooner, or a caregiver may be crumbling under immense physical, emotional, and financial strain. Both kinds of next-of-kin may seek, either consciously or unconsciously, a way to “gracefully” hasten the dying of their relative by forgoing life-sustaining treatment. Using POLST Paradigm forms makes this much easier than is possible with living wills, whose specific conditions may not apply.

Physicians do not always complete POLST forms as they interview patients. Many are completed by nurses or social workers who leave the completed form for the physician to sign as the final step for implementing orders that may forgo life-sustaining treatment. This protocol opens the possibility for another person to complete a POLST Paradigm form for a patient who lacks capacity. Some states have requirements for the person who completes the form, but often they are broad. For example, in California, a “health care provider” could include admission clerks who have no formal clinical education.<sup>111</sup>

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<sup>108</sup> See *Information and Frequently Asked Questions About POLST*, CALIFORNIA MED. ASS'N, available at <https://www.cmanet.org/about/patient-resources/end-of-life-issues/physician-orders-for-life-sustaining-treatment>.

<sup>109</sup> *Id.*

<sup>110</sup> *E.g., Frequently Asked Questions About Advance Directives*, TENNESSEE DEP'T OF HEALTH, available at <http://health.state.tn.us/advancedirectives/FAQ.htm>.

<sup>111</sup> Personal communication from attending conferences on POLST.

The following true story was related over the phone by a caregiver who gave her permission for the phone call to be recorded and to have the audio posted on YouTube.com, after the names of all involved were changed.<sup>112</sup> “Fred” was an 81-year-old man in relatively good health except for a bad ankle and “just a little” Alzheimer’s disease. One daughter warned the caregiver that the other daughter (“Carol”) was after his money. Carol “helped” her father complete a POLST and then instructed the caregiver to bring the POLST form to Fred’s doctor to sign. The caregiver knew this POLST form did not reflect the patient’s true wishes because she heard a physical therapist ask Fred if he wanted DNR or CPR and he chose CPR, but the POLST form had the DNR box checked. The caregiver brought Fred to the doctor and asked the doctor to complete a POLST form. The doctor assessed Fred and the resulting POLST form was completely different from the one that Carol had completed. The doctor’s POLST indicated that Fred wanted CPR (not DNR), and “Full” treatment including antibiotics. When Carol saw the new POLST posted on the refrigerator door, she took her father back to the doctor with the excuse that he needed a flu shot. She returned with another POLST. This one, again, indicated DNR. Carol fired the caregiver over Fred’s objections, who wanted her to stay on.

Two factors make this case unusual. First, there was a witness to the completion of the POLST form and to the patient’s previous expression of end-of-life wishes. Had the caregiver not witnessed these exchanges, no one would have ever learned about the discrepancy between the POLST orders that Fred wanted and the POLST orders that Fred (almost) got. Second, the physician maintained high professional standards. When the caregiver asked Fred’s doctor to complete a POLST form, he stated, “I am not willing to sign any POLST form before discussing it with the patient.” Unfortunately, this is not a universal practice, let alone the predominant community standard of practice.

### ***1. Are POLST forms or the way they are used responsible?***

Yes. Using the form makes it easy to forgo life-sustaining treatment on behalf of vulnerable patients. The process of completing a POLST form is in a gray zone. In most states, a surrogate decision-maker who was not designated by the patient as a person he or she does trust can sign the POLST form—even though this individual does not have the legal standing of a DPOAHC to accept and to refuse medical treatment. For the sake of expediency, witnessing requirements have been waived, including the requirement for an ombudsman where this requirement applies to Advance Directives. Expediency has thus unfortunately taken priority over protecting

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<sup>112</sup> Stanley A. Terman, *Elder Abuse Using a POLST Form: A phone interview with a caregiver in early Nov. 2012*, youtube.com (Nov. 6, 2012), available at <http://youtu.be/R-5rgqj0FOo>.

our most vulnerable patients from one of the greatest possible harms: premature dying.

## **2. Recommendations**

Physicians could be required to sign yet another statement: “The patient was provided adequate informed consent and voluntarily signed this POLST form.” Note that this statement intentionally uses the passive tense to minimize physicians’ burden; physicians need only to verify that the patient understood and agreed to what another clinician (commonly, a social worker or nurse) had previously explained. An example of a stronger physician statement is: “As the patient’s physician, *I myself* provided the patient informed consent and I witnessed her sign voluntarily.”

Alternatively, law or policy could change to require witnesses to validate the voluntary signing of POLST Paradigm forms. In recognition of the fact that many patients remain unaware of their available end-of-life options and are consequently deprived of these benefits, California,<sup>113</sup> New York,<sup>114</sup> and Michigan<sup>115</sup> have passed laws that require physicians to inform terminally ill patients about their reasonable treatment options. Given the busy schedule of physicians who care for the elderly, they may feel this is too much to ask. Perhaps not, though, given what is at stake: the patient’s life.

## **III. CONCLUSION**

### ***Pink or not, can one form be all things to all patients?***

It’s not easy being pink (or another vibrant color)—when the charge is to serve two different kinds of patients in two functional ways, as the Table on the following page summarizes.

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<sup>113</sup> CAL. HEALTH & SAFETY CODE §§ 442-442.7 (2010).

<sup>114</sup> N.Y. PUB. HEALTH LAW § 2997-c (2011)

<sup>115</sup> MICH. COMP. LAWS §§ 333.5651-.5661 (2011).

Did the now incapacitated patient previously express his/her treatment preferences?	Which of the two functions of POLST are required?	
	Do POLST forms faithfully honor the requests and instructions as previously expressed by the patient during Advance Care Planning, who expected them to be durable?	Do POLST forms respond to the patient’s current medical condition, in accordance with community standard of medical care?
<b>NO.</b> <i>There is no living will and no specific instructions to a legally designated proxy or agent by a DPOAHC.</i>	<p><b>I.</b> Clinically and ethically, it is reasonable for physicians to identify an appropriate surrogate decision-maker with whom s/he discusses decisions; and to write orders based on Substituted Judgment (if values known) or Best Interest (if values are not known).</p> <p>However the form might <b>not be effective (Potential Problem ONE)</b>.</p> <p>Relaxing standards for appointing surrogates and for witnessing opens the door to <b>potential abuse (Potential Problem SIX)</b>.</p>	<p><b>II.</b> Physicians frequently write orders based on patients’ current condition. Conflict is <i>not</i> likely if the patient did not legally designate a proxy/agent or complete a living will.</p> <p>Yet the ease with which patients can forgo life-sustaining treatment (by asking their physician to merely check a box), leads some to consider POLST forms as potentially <b>immoral (Potential Problem TWO)</b>.</p> <p>POLST forms could be used in a <b>clinically dangerous way</b> by forgoing life-sustaining treatment for patients who still want them (<b>Potential Problem FIVE</b>).</p>
<b>YES.</b> <i>The patient did previously (or has capacity and now wants to) express his/her specific treatment preferences.</i>	<p><b>III.</b> POLST forms may not reflect patients’ authentic wishes—if the forms mandate acceptance of treatment options that some patients do not want, and if the forms do not present for discussion treatment options that some patients do want (<b>Potential Problem THREE</b>).</p> <p>POLST forms may not honor patient’s wishes if the orders are NOT durable because physicians change the orders (<b>Potential Problem FOUR</b>).</p>	<p><b>IV.</b> POLST forms do not advise or warn physicians that responding to a patient’s current condition instead of honoring previously expressed treatment preferences may lead to loss of immunity (<b>Potential Problem FOUR</b>).</p> <p>If there is a conflict between the POLST form and the Advance Directive, the POLST form will prevail in most states though this violates patients’ rights of self-determination and some state laws. (<b>Potential Problem FOUR</b>).</p>

While POLST Paradigm forms probably work well most of the time for most patients, certain issues still loom. POLST forms may fail to honor patients' true end-of-life treatment preferences, and they can lead to possible abuse that, at worst, may contribute to the patient's premature death.

Almost every time Advance Directives are mentioned in POLST laws, training programs, and informational literature, this "mantra" is emphasized: "POLST forms are not intended to replace Advance Directives." Yet it seems that traditional Advance Directives are losing ground in terms of their value—as perceived by "POLST enthusiasts." It is therefore ironic that for POLST forms to be effective, moral, reflect patient's true wishes, be consistent with federal and state laws, not put patients at risk for premature dying, and minimize the potential for opportunistic abuse—it is best for a patient to complete an Advance Directive; write a statement on both the Advance Directive and the POLST form that, in the event there is a conflict, the wishes expressed in the Advance Directive will prevail; attach the Advance Directive form to the POLST form; and also upload the document to an electronic registry.