

# POLST and Patient-Centered Care: A Commentary on Grant and Anderson-Shaw<sup>1</sup>

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

- 1 This commentary regarding POLST and end-of-life medical decision-making is based upon our ongoing work both in academic bioethics and clinical ethics consultations. Of course, space limitations do not allow us to fully engage the specific details of the essays.
- 2 Martha Montello, ed. *Narrative Ethics: The Role of Stories in Bioethics*, special report, *Hastings Center Report* 44, no. 1 (2014).
- 3 The IOM (Institute of Medicine) defines patient-centered care as: “Providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions.” *Institute of Medicine, Crossing the Quality Chasm: A New Health System for the 21<sup>st</sup> Century* (Washington, DC: National Academies Press, 2001), 40.
- 4 A legitimate concern exists about how information is conveyed to the patient and the imbalance in power between a patient’s exercise of informed autonomy and the physician’s description of medical treatment options. Addressing this issue many years ago, the President’s Commission for the Study of Ethical Problems in Medical and Biomedical and Behavioral Research issued a report stating: “a professional’s careful choice of words or nuances of tone and emphasis might present the situation in a manner calculated to heighten the appeal of a particular course of action.”  
“It is well known that the way information is presented can powerfully affect the recipient’s response to it. The tone of voice and other aspects of the practitioner’s manner of presentation can indicate whether a risk of a particular kind with a particular incidence should be considered serious. Information can be emphasized or played down without altering the content. And it can be framed in a way that affects the listener—for example, “this procedure succeeds most of the time” versus “this procedure has a 40 percent failure rate.”” The report continues, “Because many patients are often fearful and unequal to their physicians in status, knowledge, and power, they may be particularly susceptible to manipulations of this type.” The Presidential Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Making Health Care Decisions: The Ethical and Legal Implications of Informed Consent in the Patient-Practitioner Relationship*, vol. 1 (Washington, DC: U.S. Government Printing Office, 1982), 67.
- 5 Edward R. Grant, “Back to the Future? POLST and End-of-Life Law,” *Examining POLST*, supplement, *Dignitas* 22, no. 4 (Winter 2015): S4-S8; and Stanley A. Terman “It Isn’t Easy Being Pink: Potential Problems with POLST Paradigm Forms,” *Hamline Law Review* 36, no. 2 (2013), 177–211.
- 6 Christian Brugger et al., “The POLST Paradigm and Form: Facts and Analysis,” *The Linacre Quarterly* 80, no. 2 (2013): 103–138; and Diane Coleman, “Full Written Public Comment: Disability Related Concerns about POLST,” submitted on behalf of *Not Dead Yet* to the Institute of Medicine’s Committee on Approaching Death, July 23, 2013, <http://www.notdeadyet.org/full-written-public-comment-disability-related-concerns-about-polst> (accessed January 13, 2016).
- 7 Gundersen Health System, “Stages of Planning,” <http://www.gundersenhealth.org/respecting-choices/about-us/>

stages-of-planning (accessed January 7, 2016).

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