

SOUNDING BOARD

Lessons from Oregon in Embracing Complexity in End-of-Life Care

Susan W. Tolle, M.D., and Joan M. Teno, M.D.

Under the incentives of fee-for-service Medicare, the utilization trends among persons with chronic progressive medical illness include more care in the intensive care unit (ICU), more hospitalizations, and often late or no referrals to hospice care (Fig. 1).¹ These utilization patterns are strikingly different in Oregon, the second state to legalize an advance directive and the first state to legalize assisted dying. In response to this legislation, the Oregon Health and Science University Center of Ethics embraced a policy of neutrality as a public position on assisted dying while using the vote as a wake-up call to the medical community to improve end-of-life care more broadly.^{2,3} The center has served as a convener of statewide education and supported the creation and dissemination of the Physician Orders for Life-Sustaining Treatment (POLST) Program.⁴ The POLST Program allows patients with advanced illness and frailty and their health care professional to document patients' preferences regarding the use of life-sustaining treatment with medical orders that can be honored across settings of care.⁵ The POLST form (see the Supplementary Appendix, available with the full text of this article at NEJM.org) is designed to ensure that patients' preferences to use or limit treatment are equally honored.⁶

Persons dying in Oregon are less likely to be hospitalized and more likely to use hospice services at home than are patients in Washington and the rest of the United States. We selected the state of Washington for comparison with Oregon because of its close proximity and comparable demographic features. Washington has similar liberal political views and racial composition of decedents, has an established POLST Program, and has also legalized assisted dying.⁷ In 2013, nearly two thirds of Oregonians who died did so at home, whereas only 39.6% of persons in the rest of the United States who died did so at home. The rate of ICU use in the last 30 days of life in

Oregon was 18.2%, as compared with 23.0% in Washington and 28.5% in the rest of the United States (Fig. 1). Patients who were hospitalized in the last month of life were more likely to be discharged home in Oregon than in Washington or the rest of the United States (73.5% in Oregon vs. 63.5% in Washington and 54.2% in the rest of the United States).

It is difficult to disentangle the reasons behind the differences in care at the end of life in Oregon as compared with other states, but we think that the differences in care reflect the complexity and intensity of the initiatives developed in coordination with the POLST Program. Although Washington also has an established POLST Program, it has not developed educational materials, coordinated cross-system conferences, conducted research, and maintained a statewide registry, as extensively as Oregon has done. In this article, we describe the policy changes and educational efforts to improve end-of-life care that were launched in Oregon at the levels of state government and local health systems (Table 1). (Fig. S1 in the Supplementary Appendix provides a timeline for the initiative in Oregon.) We will also outline some of the lessons learned from the successes in Oregon. Transforming care near the end of life requires a willingness to forgo the temptation of an easy fix by merely implementing the use of the POLST forms. Until we embrace the complexity of this social interaction, the need for multifaceted interventions, and the application of public health strategies, we will fail to make the needed improvements in care at the close of life.

Advance care planning and the use of POLST forms is important, but if patients' goals are not linked to actionable care plans that are supported by local health care systems and state regulation, many patients who wish to remain at home will die intubated in the hospital for all the reasons the current system fails them.^{8,9} Consider

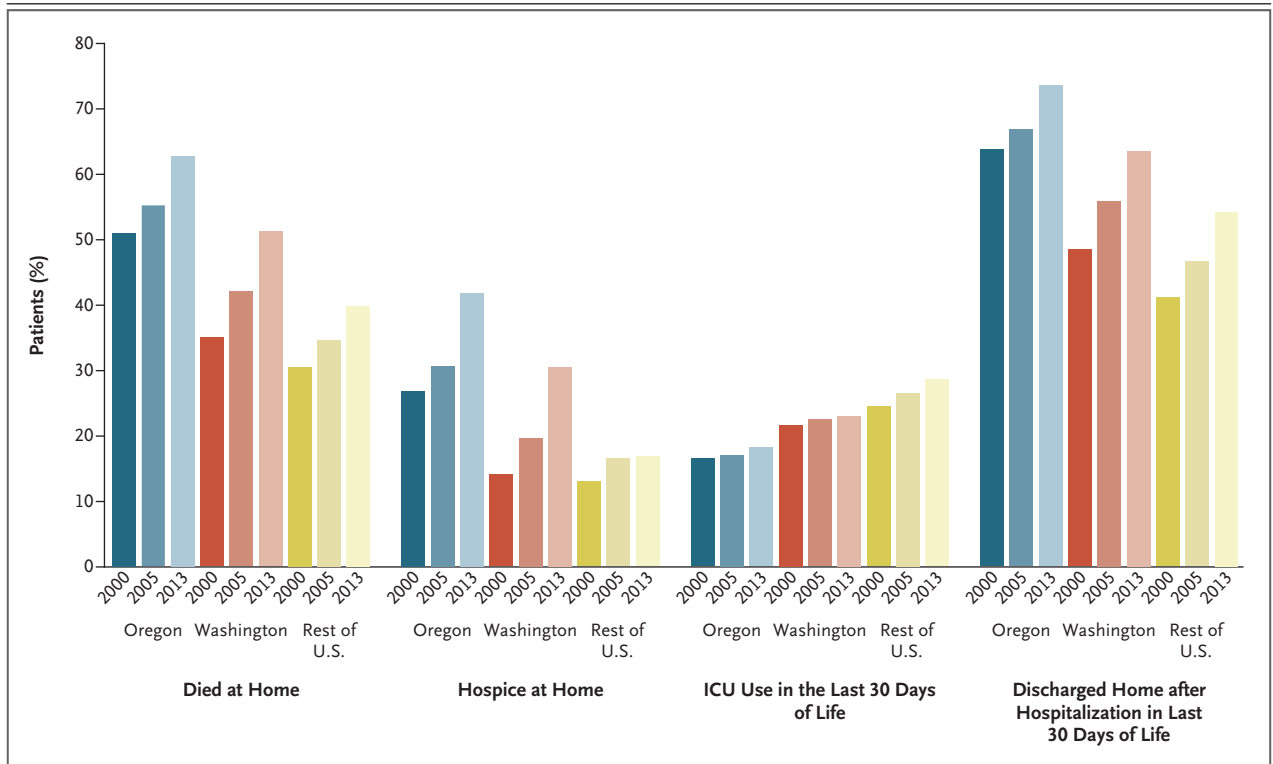


Figure 1. Deaths among Fee-for-Service Medicare Beneficiaries in Oregon, Washington, and the Rest of the United States.

The graph shows changes between 2000, 2005, and 2013 in the rates of death among fee-for-service Medicare beneficiaries in Oregon, Washington, and the rest of the United States (U.S.). Shown are the proportions of patients who died at home, who received hospice services at home, who received care in an intensive care unit (ICU) during the last 30 days of life, and among patients who were hospitalized during the last 30 days of life, the proportion who were discharged home.

the following composite case story, which illustrates the complexity, breadth, and depth of systems changes that are needed to ensure that patient preferences are consistently honored.

Edith, an 84-year-old white woman with oxygen-dependent chronic obstructive pulmonary disease, completed a POLST form after being counseled by her primary care physician. The form recorded her wishes that she would not be resuscitated or placed on mechanical ventilation. Despite having 24-hour care at home, she fell and fractured her hip. Emergency medical services (EMS) providers were called, and they accessed her POLST form from the Oregon POLST Registry. Edith was transported to a regional trauma center, where her condition deteriorated and there were concerns that she might need to be intubated. Per protocol, the trauma surgeon was notified of her POLST form specifying the do-not-resuscitate orders and the use of comfort measures only by accessing documentation in

the POLST Registry that provided clear evidence of her wishes. Edith was cared for by the palliative care team in the emergency department with the use of opiates to relieve her pain and dyspnea, and she was transferred home with hospice services, where she died, comfortable and surrounded by her family. The key interventions in Edith's care that made her death at home possible included strategic interventions at four levels that are aimed at the individual person and their health care professional, the local health care system, cross health system collaboration, and state government (Table 1).

INTERVENTIONS AIMED AT INDIVIDUAL PERSONS

Extensive local media coverage, public education, and the experience of friends in her community made Edith and her family aware of their options for advance care planning and support for

Table 1. Key Interventions and Effects on Care of Patients.*

Level and Intervention	Application to Edith's Experience of Dying
Individual persons and their health care professionals	
Public education through media coverage and local community events	Raises Edith's awareness to complete a POLST form with her health care provider and discuss plans with daughter
Education of health care professionals about communication and completion of POLST forms	Facilitates sensitive communication and proper completion of the POLST form as well as creation of an action plan to honor the patient's preferences
State government	
Creation of Registry and enactment of regulation that allow EMS to honor POLST forms	Ensures that EMS is able to obtain Edith's POLST form and honor those wishes in the field
Quality monitors at the Registry in place to ensure the accurate completion of POLST forms	Ensures that POLST forms are completed correctly
Local health care system	
Change in culture to support health care professionals in counseling patients and the completion of the POLST forms	Values the time spent in the completion of the Edith's POLST form
Registry raises awareness to review the POLST forms in medical decision making; EMR of the health care system provides an alert that made the health care professionals aware of the patient's POLST form	Ensures that Edith's POLST form is available to the surgeon, who decides with Edith's daughter not to operate; in her medical record, EMR prominently provided an alert that made all health providers aware of the patient's advance directive
Arrangement by local hospice for services for a dying person at home in transition from an acute care hospital	Ensures that Edith receives home hospice services that allow her to die at home, comfortable and surrounded by her family
Local champions and state coalition	
Ability to solve system and regulatory barriers nimbly and quickly	Champions played a key role in changing regulations to allow EMS to honor the POLST form and enhance hospice capacity to take admissions from the emergency department to home
Development of educational tools and identification of patients' stories	Enables design of educational interventions and hosting of regional conferences
Coordination of the implementation of systems change as a result of quality-improvement efforts	Promotes collaboration and conduct quality-improvement efforts across various settings of care

* Shown are key interventions, such as policy changes and educational efforts at various levels of local systems and government, to improve end-of-life care in Oregon and their effects on the care of a case-study patient (Edith). EMR denotes electronic medical record, EMS emergency medical services, and POLST Physician Orders for Life-Sustaining Treatment.

person-centered care. The Center for Ethics has hosted more than 200 conferences for health care professionals about ethics, palliative care, and communication skills.¹⁰ The development of educational resources such as the *Understanding POLST* video and lay brochures made talking with her primary care professional a process rather than a single discrete event (Fig. S1 in the Supplementary Appendix).¹¹ Approximately 8 years before her death, Edith told her doctor that she wanted her daughter to be her surrogate. When Edith required oxygen support at home, her doctor encouraged her to complete an advance directive. At a visit 1 month before her death, Edith talked about never wanting to be intubated again, and

she and her doctor completed a POLST form after she and her daughter watched the *Understanding POLST* video with a clinic social worker. Edith's primary care physician counseled Edith about her prognosis and treatment options, and through shared decision making they documented her treatment goals. The physician then worked with Edith's family to develop a plan that would allow her to remain at home with 24-hour care. The completion of her POLST form was not a single event but was part of a multistep process that was facilitated by her primary care team.¹² Key to Edith's care was that her EMS providers and all the members of her primary care team had been trained in how to record preferences for

care accurately on the POLST form and in the importance of honoring those preferences.

INTERVENTIONS AT THE LOCAL
HEALTH CARE SYSTEM AND STATE
GOVERNMENT LEVELS

The process of creating and documenting POLST orders serves as a tool to record conversations regarding goals of care, but in isolation this process is not sufficient to ensure that Edith's wishes will be honored once she leaves her home. The creation of systems to ensure that health care professionals are aware of the directives and that EMS providers are able to honor those wishes is equally important. In Edith's case, the ability of EMS providers and the local health care system to obtain and honor her POLST form was key. In Oregon, state regulations allow EMS providers to follow the directives of a POLST form and to honor a person's wishes by not intubating or resuscitating the patient.¹³ Similarly, although the physician who signed Edith's POLST form did not have admitting privileges at the trauma facility, Oregon Medical Board regulations ensured that the orders could be honored.¹⁴ The trauma-system protocol enabled the POLST form to be obtained for the surgeon and other health care professionals to use in decision making.

In addition, Edith's physician was supported by a culture that valued team collaboration, and the health care team had participated in systems integration of educational materials to enhance patients' participation in goals-of-care planning, which optimized Edith's understanding and used the physician's time effectively. The electronic medical record (EMR) tagged the POLST forms, linking them to the patient-information header that alerts all the members of the health care system to the presence of the patient's POLST form.¹⁵ A separate EMR tag confirmed the presence of the advance directive, and each form could be viewed with a single click, making her wishes clear as Edith moved from one care setting to another.

LOCAL CHAMPIONS
AND STATE COALITION

Champions who are part of state coalitions can be nimble and help to address key leverage points in ensuring that patients' wishes are honored as

transitions occur across care settings and that persons wishing to die at home have excellent palliation with hospice providers who are able to respond to the need for timely referrals. Education is important both within health systems and statewide, but local champions also play a vital role in removing system barriers, particularly in addressing barriers across care settings. The timeline in Figure S1 in the Supplementary Appendix shows a few of the dozens of interventions that have been facilitated by champions and coalition members. The development of educational tools and the removal of barriers are not enough. Even with an exemplary advance care planning process in place, if the patient and family do not have timely access to home hospice care, the advance care planning process may be of little value. If hospice had not been able to enroll Edith within 24 hours after her discharge, it would not have been possible for her to be discharged home from the emergency department observation unit.

Narrative stories are important in helping stakeholders understand the effect of each change in improving care, and these stories have proved to be vital to public education and media engagement. However, anecdotal case reports are not sufficient for the evaluation of success. We also need to track quality rigorously and to prevent unintended consequences. Oregon is currently using version 11 of the POLST form. Changes are made to the form by the statewide POLST Program coalition after extensive review to respond to new research data and changes in statutes or regulations and to address the use of new medical treatments. End-of-life champions in Oregon advocate broadly for improvements in best practices. When data showing that tube feeding did not extend life or enhance comfort in persons with advanced dementia,¹⁶⁻¹⁹ broad and far-reaching public health efforts were implemented in the 1990s and were used to discontinue the practice. The effectiveness of these efforts is associated with remarkably low rates of tube-feeding use in Oregon, dating back to 2000.²⁰

Finally, to sustain change from the beginning requires a stable financial base, leadership, and an administrative home. Although private philanthropy funded the development of the innovative POLST Program in Oregon, the Registry operations are now funded by the state, and the Oregon POLST Program is building an endowment

to sustain operations. The Center for Ethics in Health Care, which administers the Oregon POLST Program and coordinates efforts to improve end-of-life care statewide, does not accept funding from health care industry sources. Important to the success of this work is the public trust that efforts are being made to honor patients' preferences and improve quality rather than to cut costs. The public trust can be damaged when incentives appear to have cost savings rather than patients' wishes as their primary goal (e.g., Liverpool Care Pathway of the Dying Patient and "death panels").²¹

Without a complex, multifaceted, and longitudinal set of interventions, Edith would have been intubated and would probably have died in an ICU, and the high rate of death at home with hospice in Oregon might look more like the rate in Washington (Fig. 1). Although Oregon has made great strides, our systems are far from perfect. One-click access to the POLST form in the EMR is not yet available in most hospitals. We are aware that finding Edith's POLST form was important to her achieving her wishes, but it was not sufficient. Replication of the experience in Oregon requires the development and adoption of interventions at every step in this complex medical and social interaction. With alignment of our health care systems incentives for value (i.e., quality and health care expenditures) over volume of services, fundamental change and improvement are within our reach. We must embrace the complexity, develop dynamic and multifaceted interventions, track the quality of care, and embed these interventions in the local and national health care culture, while avoiding incentives that might undermine the public trust and integrity of the process.

Disclosure forms provided by the authors are available with the full text of this article at NEJM.org.

From the Division of General Internal Medicine and Geriatrics and the Center for Ethics in Health Care, Oregon Health and Science University, Portland (S.W.T.); and the Division of Gerontology and Geriatric Medicine and Cambia Palliative Care Center of Excellence, University of Washington, Seattle (J.M.T.).

1. Teno JM, Gozalo PL, Bynum JP, et al. Change in end-of-life care for Medicare beneficiaries: site of death, place of care, and

health care transitions in 2000, 2005, and 2009. *JAMA* 2013;309:470-7.

2. Tolle S. Measure 16: A wake-up call to medicine. *The Sunday Oregonian*. November 13, 1994:C1, C4.

3. Lee MA, Tolle SW. Oregon's assisted suicide vote: the silver lining. *Ann Intern Med* 1996;124:267-9.

4. Oregon POLST history. Portland, OR: Physician Orders for Life-Sustaining Treatment (POLST) (<http://www.oregonpolst.org/history>)

5. Hickman SE, Nelson CA, Moss AH, Tolle SW, Perrin NA, Hammes BJ. The consistency between treatments provided to nursing facility residents and orders on the physician orders for life-sustaining treatment form. *J Am Geriatr Soc* 2011;59:2091-9.

6. Fromme EK, Zive D, Schmidt TA, Cook JN, Tolle SW. Association between Physician Orders for Life-Sustaining Treatment for Scope of Treatment and in-hospital death in Oregon. *J Am Geriatr Soc* 2014;62:1246-51.

7. Gallup state of the states (<http://www.gallup.com/poll/125066/State-States.aspx>).

8. Institute of Medicine. *Dying in America: improving quality and honoring individual preferences near the end of life*. Washington, DC: National Academies Press, 2015.

9. Gozalo P, Teno JM, Mitchell SL, et al. End-of-life transitions among nursing home residents with cognitive issues. *N Engl J Med* 2011;365:1212-21.

10. OHSU Center for Ethics in Health Care home page (<http://www.ohsu.edu/xd/education/continuing-education/center-for-ethics/>).

11. Oregon POLST patient & family resources. Portland, OR: Physician Orders for Life-Sustaining Treatment (POLST) (<http://oregonpolst.org/patientfamilyresources>).

12. Tolle SW, Back AL, Meier DE. End-of-life advance directive. *N Engl J Med* 2015;372:667-70.

13. Oregon Medical Board. Oregon Administrative Rule 847-035-0030 (http://arcweb.sos.state.or.us/pages/rules/oars_800/oar_847_035.html).

14. Oregon Medical Board. Oregon Administrative Rule 847-010-0110 (http://arcweb.sos.state.or.us/pages/rules/oars_800/oar_847_010.html).

15. Zive DM, Cook J, Yang C, Sibell D, Tolle SW, Lieberman M. Implementation of a novel electronic health record-embedded Physician Orders for Life-Sustaining Treatment system. *J Med Syst* 2016;40:245.

16. Teno JM, Gozalo PL, Mitchell SL, et al. Does feeding tube insertion and its timing improve survival? *J Am Geriatr Soc* 2012; 60:1918-21.

17. Mitchell SL, Tetroe JM. Survival after percutaneous endoscopic gastrostomy placement in older persons. *J Gerontol A Biol Sci Med Sci* 2000;55:M735-M739.

18. Teno JM, Gozalo P, Mitchell SL, Kuo S, Fulton AT, Mor V. Feeding tubes and the prevention or healing of pressure ulcers. *Arch Intern Med* 2012;172:697-701.

19. Finucane TE, Christmas C, Travis K. Tube feeding in patients with advanced dementia: a review of the evidence. *JAMA* 1999;282:1365-70.

20. The Dartmouth Atlas of Health Care. Percent of decedents with dementia receiving a feeding tube during the last six months of life (by state). 2012 (<http://www.dartmouthatlas.org/data/map.aspx?ind=355>).

21. Teno JM, Gozalo PL. Quality and costs of end-of-life care: the need for transparency and accountability. *JAMA* 2014;312:1868-9.

DOI: 10.1056/NEJMs1612511

Copyright © 2017 Massachusetts Medical Society.