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Oregon's POLST form helps clarify end-of-life decisions

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If you were 90 and your heart was failing, would you want a hospital to do everything it could to keep you alive? Or would you just want your pain controlled while nature took its course?

Whatever your answer, a new study suggests that a form developed in Oregon may be the best way to record it.

Oregon doctors developed the POLST form -- **Physician Orders for Life-Sustaining Treatment** -- in the 1990s to address shortcomings of other "advance directives," such as living wills or notes in medical charts. Very ill or elderly people create those directives to outline treatment they want to have or avoid in a medical crisis. But those forms can be hard to find in an emergency or too vague to be useful. In contrast, POLST forms are brightly colored for visibility, can be logged in an electronic registry and have check-boxes to record specific preferences for several treatments, including the use of antibiotics, oxygen, feeding tubes and intravenous hydration.

"POLST really offers a systematic way for people...to talk about what they want and don't want, and get that documented," said Susan Hickman, who teaches nursing at Oregon Health & Science University and Indiana University.

And POLST forms are signed by a doctor, nurse practitioner or physician assistant, giving them weight in the medical world.

"That's what makes it an order, and that's what makes it work," said Dr. Susan Tolle, director of **OHSU's Center for Ethics in Health Care**. "It turns an advance directive into action."

The POLST form is popular: Tens of thousands Oregonians have one of the orders, and more than 30 states have or plan similar programs. But the form had never been tested head-to-head against chart notes or other, more traditional medical directives. So Hickman, Tolle and other scientists used a \$1.4 million federal grant to track treatment for more than 1,700 long-term nursing home residents in Oregon, Wisconsin and West Virginia, with an average age of 84. Roughly half of them had POLST forms. Looking over 60 days' worth of records, the researchers compared what medical treatments people got to what preferences they recorded. They also checked how often patients reported pain or shortness of breath, since some people have worried that patients who want limited end-of-life care get less "comfort care" to ease discomfort.

Nursing home residents without POLST forms in the study were far less likely to have detailed records of the care they wanted. One in eight residents without POLST had no recorded preferences about any life-sustaining treatment

-- surprisingly high, since everyone studied was in fragile health, Hickman said.

The other 87 percent of non-POLST users had discussed some end-of-life care, usually just whether they wanted CPR if their hearts stopped. Less than 14 percent said whether they wanted intensive hospital care, antibiotics, feeding tubes or other interventions. Oregon's POLST form lets people check whether they always want those interventions, want them only in limited cases or want to avoid them.

Recording preferences made a difference in the study: POLST users who wanted only "comfort care" measures in a hospital were 59 percent less likely to receive life-sustaining treatments than residents with traditional do-not-resuscitate orders, the researchers wrote in today's *Journal of the American Geriatrics Society*. People whose POLST specified full treatment got just as much care as people who had other requests for full treatment. The study also found no statistically significant difference in how many days POLST users and others spent in pain or short of breath, Tolle said.

One area where POLST didn't make a difference was antibiotics: About a third of the nursing home residents studied got those drugs whether or not they had POLST forms, and whether or not they asked to avoid antibiotics. Tolle guessed that might be because antibiotics are sometimes part of the "comfort care" all sick patients get, for instance to fix a painful but not life-threatening infection.

The study should help inform national debate about end-of-life care. About a dozen states run POLST programs and "there seem to be a huge number of states, perhaps 25 others, that are looking at adopting it," said Naomi Karp, a senior policy adviser at **AARP's Public Policy Institute**. AARP backs POLST "to encourage that the wishes of patients with advanced, chronic, progressive illness" are honored, Karp said. An American Bar Association commission and AARP are studying how 12 states have implemented POLST and plan to write a report helping other states create programs.

Karp said she was glad the study found no significant difference in symptom and pain management among POLST users. And it's good that POLST users who want full care got it, she said: "Part of why we support POLST, and part of the beauty of it, is it's really value-neutral in terms of the kind of care people are choosing."

While other states start using POLST, Oregon is trying to perfect its system. The POLST is popular here; Tolle estimated that more than 80 percent of Oregon nursing home residents have one. But outside of an institution, it's not always easy for paramedics or other caregivers to find a form when needed. So Oregon has started a searchable electronic POLST registry, which now holds roughly 25,000 records.

The registry appeals to Kaye Hanni, whose mother's POLST form was locked away when it was needed. Wanda Puckett was at home in Union in December 2001, when a weak, swollen spot in her aorta broke. A neighbor rushed her to a hospital in La Grande, which sent her by Life Flight to OHSU Hospital. Puckett's POLST form stayed locked in a filing cabinet in Union, where doctors couldn't see it, while she was hooked to machines and "being miserable," Hanni said.

"She was as independent as a hog on ice," Hanni said. But in the hospital, "she didn't know where she was or what she was doing."

After six days, Hanni and her brother worked with doctors and got the life support removed; Puckett passed away within five minutes.

"If they'd had that POLST form at La Grande, they would have done what they could to keep her out of an urgent situation, but they would have let it take its course," Hanni said. As to the registry, "I just think it's a huge blessing."

-- **Andy Dworkin**

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