Changing End-of-Life Planning: The Oregon Experience

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ABSTRACT

Large state-by-state variations exist in location of dying and level of aggressive treatment during the final phase of life. This paper describes Oregon’s incremental gains toward improving advance planning for end-of-life care in a state with the lowest rate of in-hospital deaths. Action strategies have required data gathering and reporting, and coalition building with a focus on systems change. Also, public education through the news media has proved to be a vital component of Oregon’s process of change. The impact of media coverage is complemented by continuing education for health professionals. Special efforts are still needed to improve access to the Physician’s Orders for Life-Sustaining Treatment program (POLST) for some rural, minority, and pediatric populations and for persons living at home with a diagnosis other than cancer. However, with enough time, a sustained effort, and a broad coalition of partners, profound change is possible.

INTRODUCTION

Changing the organizational culture and systems approach to health care delivery is a slow and incremental process in all areas of clinical care, including end-of-life care. This paper describes Oregon’s gains toward improving advance planning for end-of-life in a state with the lowest rate of in-hospital death.\(^1\)\(^–\)\(^3\) We review how long it has taken to make and measure change in advance planning, processes that have achieved change, and remaining challenges toward continued improvement in advance planning. The paper’s focus is on identifying critical forces that have impacted, or at least been concurrent with, changing trends over time, and on identifying short-term goals yet to be achieved.

Both professional reports\(^4\) and the popular press\(^5\) document evidence of medicine’s proclivity toward intensive care. Cardiopulmonary resuscitation and intensive care often are provided during life’s final months even when the patient’s or family’s preference is for palliative rather than life-extending treatments.\(^4\)\(^,\)\(^6\) Surveys indicate the personal distress of nurses and physicians about their frequent involvement in overly aggressive treatment of the dying.\(^7\) These concerns have led to appeals for increased advance care planning and better documentation of treatment refusal.\(^8\)

Numerous studies have highlighted the inadequacy of advance directives in assuring that patient wishes are followed.\(^9\)\(^–\)\(^11\) Some investigators have argued that advance directives are not specific enough to direct actual clinical decisions.\(^10\) Most clinical intervention studies have been unable to change the degree to which patient wishes are followed in avoiding aggressive treatment at end-of-life.\(^9\) Thus, institutional programs and systems innovations are needed to bring about meaningful and measurable change.

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The views expressed are those of the authors.
THE HISTORY OF ADVANCE PLANNING IN OREGON

Regional differences are dramatic in end-of-life care across the United States. Geography seems to impact the level of aggressiveness of care in life’s final months. Large state-by-state variations exist in location of dying and level of aggressive treatment during terminal phases. These differences reflect the wide variation in culture of care delivery and citizen expectations across the United States. In Oregon, multiple factors have contributed to high rates of advance planning, and we review this history here.

Change in public knowledge

Public knowledge in Oregon about options in care at the end of life has increased dramatically over the past 15 years. Since the mid-1980s, Oregon Health Decisions has conducted major outreach activities and distributed advance directives information through faith communities, train-the-trainer programs, and town meetings. Then, in 1994 and again in 1997, the public was bombarded with intense media campaigns related to Oregon’s two citizen votes on the physician-assisted suicide Death With Dignity Act. Much of the information given in these campaigns educated the public about end-of-life care options other than suicide. For example, multi-page articles in the statewide newspaper, The Oregonian, described hospice, how it works, who benefits, and how to enroll. Explicit information was provided about choices at the end of life, with detailed information about advance directives and their effectiveness. Such media coverage tended to facilitate conversations within families and between patients and providers, and increased the general sense of empowerment of the public in a citizen’s right to serve as decision maker for him or herself and to authorize loved ones to make choices about end-of-life treatments.

Changes in rates of advance planning

Oregon has remarkably high rates of written advance directives and do-not-resuscitate (DNR) orders. Outreach efforts and educational programs have made a measurable difference in the number of people making their wishes about life-sustaining treatments known ahead of terminal illness. Family surrogates often are made aware of the patient’s wishes, and they feel empowered in assuring that wishes are respected.

Rates of do-not-resuscitate orders for residents in Oregon nursing homes have been high for a long time. Data collected in 1993 by Teno and colleagues in their multistate, 10-city study of DNR orders in nursing homes indicated that 70% of Portland, Oregon, nursing home residents had DNR orders. Three years later, 1996 data from a study by Tolle et al. of eight nursing homes in Oregon indicated that 91% of nursing home residents had a written DNR order.

High rates of advance planning are common not only for those in nursing homes, but for all who die in Oregon. In a 1997–1998 study by Tolle et al. of 475 randomly selected Oregon decedents, 67% of family informants reported that the decedent had a written advance directive that indicated wishes regarding the use of life sustaining treatment. In addition, whether or not a decedent had a written advance directive, 93% of study families believed they knew what their loved one wanted regarding life-sustaining treatment. Also, families reported that decisions not to start treatment occurred far more frequently than decisions to withdraw treatment (79% vs. 21%), which further reflects advance planning.

One indicator of the effect of advance directives versus rate of completion, was found in a study by Tilden et al. on families of hospitalized patients who participated in decisions to withdraw life-sustaining treatments. Stress levels in family members of patients whose deaths followed treatment withdrawal were extremely high. However, when decedents had earlier completed an advance directive, family stress was dramatically and significantly lower than when decedents had not made their wishes known.

Changes in location of death and associated cost of inpatient care

In 1980, 50% of Oregonians of all ages died in an acute care hospital. In 1993, the percentage had dropped to 35%, compared to 56% for all Americans; by 1999, Oregon’s average was 31%. Presently, Oregon has the lowest rate in the United States for in-hospital deaths. In Bend, Oregon, a midsize community, only 17.2% of those over age 65 die in an acute care hospital. With these changes, there has been a substantial increase in both death at home and death in long-term care facilities. These proportions in location
of death in Oregon, which are dramatically different compared to many parts of the country, have occurred gradually over time.

Pritchard and colleagues noted the powerful association between low rates of acute care bed availability per 1,000 population and low rates of in-hospital death. The converse is also true. When bed availability approaches 5 per 1,000 residents, death in hospital is frequently as much as twofold or more what it is in the Portland area, where the bed availability is 1.9 per 1,000. However, other factors also are at work, because some locations with low bed availability have high rates of in-hospital deaths. The use and availability of resources, such as home hospice, which support a comfortable death out of the hospital, also impact location of death.

Oregon’s position at the low end of the national range on in-hospital deaths raises questions about the possibility of undertreatment. Given Oregon’s high penetration of managed care, how often are patients denied treatments they would have preferred to receive? How satisfied are patients and their families with the amount of aggressive treatment they receive at the end of life? Our interview data from family members of 475 recently deceased patients indicated that families overall were pleased with the level of treatment the patient had received.

Regarding aggressiveness of life-sustaining treatment, the vast majority of family members said the right amount had been used. Only 2.4% of families reported “too little” had been done and 4.6% felt that “too much had been done.” These findings compare with an earlier study, based on 1984 data, in which 15% of families reported that too much aggressive treatment had occurred. Thus, it appears that family satisfaction is high with regard to respect for treatment decisions about the amount of life-sustaining treatment.

The national trend toward out-of-hospital death has substantial cost implications. Oregon has the lowest rate of inpatient expenditures in the final 6 months of life per Medicare enrollee. Medicare data confirm that there is nearly a three-fold difference in in-patient expenditures during the final 6 months ($6,198 per enrollee in Bend, Oregon, vs. $17,797 per enrollee in New York City). Given that satisfaction with the level of care and the amount of life-sustaining treatment is remarkably high in Oregon, these cost savings are noteworthy.

THE PROCESS OF CHANGE

Assuring that patient wishes are followed requires organizational systems that translate patients’ preferences into physicians’ orders. Medical orders that are standardized and formatted increase the likelihood that they will be respected on transfer across care settings. The system in Oregon that achieves this, a program called the Physician Orders for Life-Sustaining Treatment (POLST), is an example of the coalition process and product that results in statewide change, and ultimately, in measurable differences in patient care.

In the spring of 1991, at a statewide meeting of Oregon ethics committee members, concern was raised about the problem of respecting DNR orders when patients were transferred from a nursing home to a hospital. Anecdotes were told about nursing home residents who wanted palliative care at their nursing home, but, on a sudden medical event such as pneumonia, were transferred to a hospital intensive care unit (ICU). Usually, patients’ pertinent nursing home records related to end-of-life, such as DNR orders and advance directives, did not accompany the patient or could not be respected in the ambulance on transfer or at the acute care hospital. Families often were outraged, and ethics committees frequently intervened so that unwanted treatments could ultimately be withdrawn.

In the fall of 1991, a multidisciplinary task force coalesced to address the problem of limiting unwanted transfers and preventing unwanted intensive medical interventions. The task force spent its first 2 years examining the scope of the problem and ensuring that all appropriate stakeholders were at the table. Task force membership included emergency medical personnel, hospice leaders, representatives from senior and disabled services, primary care providers, leaders from the long-term care industry, legal counsel, and health services researchers. The task force determined that a voluntary, transferable form was needed that would indicate POLST. The goal was to develop a form that would be respected on transfer across treatment settings statewide. Initial versions of the form were extensively tested with primary care providers and emergency medical personnel to ensure that the POLST form did not result in inappropriate withholding of life-sustaining treatment. Pilot testing was then done in selected long-term care facilities in three communities. In early versions of the POLST form,
wording introduced communication problems. For example, the language of the initial POLST form was too similar to emergency medical personnel protocols, (e.g., “Care Level 1”) and less like the language of hospice care (e.g., “comfort measures only”), which reduced the form’s usefulness for nursing home personnel. A 5-year period was required for the POLST task force to develop, refine, and extensively test the POLST form. Not until 1996 did extensive statewide dissemination occur, and with it, a statewide 1-year prospective study of eight long-term care facilities to assess the effectiveness of the POLST form. In this prospective study, nursing home residents were selected if they had a POLST form marked “do not resuscitate,” “comfort measures only,” and “transfer only if comfort measures fail.” One hundred eighty residents were followed for 1 year for medical events, treatments, and outcomes, including death. No study subject received cardiopulmonary resuscitation (CPR), ICU care, or ventilator support. Of the 38 subjects who died during the study year, 63% had an order for narcotics, and only 2 died in an acute care hospital. A total of 24 subjects (13%) were hospitalized during the year. The overwhelming majority were hospitalized because the nursing home could not control suffering, and in only 4 cases was the POLST overridden with the transfer being to extend life.

Armed with these findings regarding the effectiveness of the POLST form, the POLST Task Force worked with the Oregon Board of Medical Examiners to revise the Scope of Practice for Emergency Medical Personnel. EMS Scope of Practice was modified to state that, “Emergency personnel shall respect written physician or nurse practitioner orders regarding life-sustaining treatment.” This ensured the legal protection of EMS personnel, when following POLST orders in the field, and alleviated concerns of legal counsel in some counties.

At present, the POLST Task Force continues to meet bimonthly and, approximately every 2 years, makes minor modifications in the POLST form. The current major activity of the POLST Task Force is statewide education. Initially, educational efforts targeted only health care providers. More recent efforts also target the general public and have been covered by the news media. As a result, family members, when appointed via advance directives as surrogate decision makers, increasingly anticipate they will someday be working with the patient’s physician to turn the wishes of the patient into action by requesting that the physician complete and sign a POLST form.

Thus, from a general awareness in 1991 of a common problem, the POLST Task Force has seen the POLST program grow in a decade to broad statewide participation of long-term care facilities and home hospice programs. The Oregon Health & Science University Center for Ethics in Health Care, which distributes the POLST form on request, has filled orders for over 450,000 POLST forms, which is remarkable given that less than 30,000 Oregonians die each year. Some hospitals now mandate the completion of a POLST form at discharge for patients transferred to long-term care facilities, other institutional settings, or home hospice. Although now extensively used, it has taken nearly a decade to move from development and pilot testing to implementation and statewide utilization. Furthermore, the POLST program continues to face challenges to implementation in some populations, as described below.

**FUTURE CHALLENGES**

While Oregon has made tremendous progress in advance care planning, the progress is not uniform and some patient groups and institutions are underserved. State census data indicate that 15% of Oregonians are race other than Caucasian, although only 4% of those who die in Oregon are minority, in part because many immigrants return to their country of origin when they develop a life-threatening illness. Thus, advance planning for some involves receiving information about the severity of their condition in time to plan and make an international move.

How this information is delivered and to whom varies by individual but also by cultural tradition. For example, some Asian groups hold a tradition of telling family members, rather than the patient, the bad news of a terminal diagnosis. The family participates in the informed consent process about treatment options, then makes treatment decisions such as whether to have the patient return to the homeland or receive treatments in the United States. Difficulty in talking openly about prognosis has made implementation of POLST more difficult. Other factors that have made the POLST form less effective with minority groups are that, statistically, ethnic minority groups are more likely to
die in an acute care hospital\textsuperscript{3} and are enrolled in hospice less frequently. At times cross-cultural sensitivity and communication falter, and trust is compromised. Helping patients and families make advance plans in line with their deeply held views and wishes requires cultural sensitivity and new skills for health care providers. Oregon and other states with smaller minority populations look to states such as California, where coalitions have focused specifically on the needs of minority communities in end-of-life care. The POLST Task Force plans to expand its statewide educational activities for health professionals to include more cross-cultural focus. The Task Force also plans to translate the lay version of the POLST brochure into Spanish. Culturally respectful outreach programs are needed to facilitate advance planning and to enhance culturally sensitive end-of-life care.

A second challenge is that not all communities and hospitals throughout Oregon are equally involved in advance planning, and the use of the POLST is low in some areas. For example, one smaller hospital in the Portland metropolitan area has higher rates of ICU use and in-hospital death in the final 6 months of life than all other area hospitals.\textsuperscript{12} Data for this hospital’s catchment area look less like the rest of Oregon and more like much of the East Coast in resource use in the final 6 months of life. This institution is not yet part of the POLST program.

Additionally, a few health systems in some rural regions appear hesitant to endorse POLST, although their numbers are shrinking every year. The POLST Task Force has developed a short monograph that addresses commonly asked questions and helps to overcome reluctance of these health professionals, as well as helps guide colleagues at a national level who wish to develop similar programs. In addition, we continue to expand our efforts at public education. As members of the public become more knowledgeable about the use of advance directives and the role of POLST in assuring that their loved one’s wishes are followed, family members become more assertive with physicians to encourage their use of the POLST.

Health systems can support and guide physicians in using the POLST by designing policies that assure that patients uniformly will be asked about their wishes regarding life-sustaining treatments and have their wishes recorded. For example, a growing number of acute care hospitals are mandating that POLST forms be completed on all patients prior to discharge to a home hospice program or a long-term care facility. Most home hospice programs and long-term care facilities complete a POLST form as part of the process of admission or enrollment. The POLST Task Force continues to reach out to those smaller programs that are not yet participating in the POLST Program.

Patients with certain diagnoses represent another hard-to-reach group. The patient’s underlying diagnosis impacts whether they are more or less likely to complete an advance directive. Among Oregonians who die of cancer, 70% die at home.\textsuperscript{3} Persons dying of cancer are far more likely to complete an advance directive, to have their physician sign a POLST form, and to die at home under hospice care. On the other hand, persons dying of heart disease are less likely to complete an advance directive, less likely to enroll in hospice, and more likely to die in an acute care hospital. A challenge for the POLST program is to reach more people with diagnoses other than cancer but whose death would not be a surprise within the following year. Patients with advanced heart disease, for example, would benefit not only from the POLST program but also from revisions of Medicare hospice admission requirements.

Finally, the Task Force recently modified the POLST for use in the care of dying children. Oregon law has no specific prohibitions on the use of POLST in the care of terminally ill children. Having conversations with parents about prognosis and setting limits on life-sustaining treatments in dying children requires a high level of skill. Not having these conversations contributes to ongoing aggressive treatment and high rates of suffering in dying children.\textsuperscript{25} POLST Task Force members are concerned about the special needs of both parents and pediatric health care providers. Educational programs are underway to help those caring for seriously ill and dying children to understand when the POLST Program may be useful and how to sensitively start the conversation.

**SUMMARY**

Nationally, changes are underway toward improving advance planning for end-of-life, however, progress takes time. The Institute of Medicine estimates that an average of 17 years is required for new knowledge, generated by randomized
controlled clinical trials, to be incorporated into practice. Many organizations, such as Last Acts, Project on Death in America, The Greenwall Foundation, The Nathan Cummings Foundation, the EPEC Project of the American Medical Association, and the ELNEC Project of the American Association of Colleges of Nursing, are researching and educating to improve end-of-life care.

The process of changing Oregon’s rates and effectiveness of advance planning has been incremental over more than a decade, and has required a multifactorial, multidisciplinary approach. Action strategies have required data gathering and reporting, and coalition building with a focus on systems change. Also, public education through the media has proved a vital component of Oregon’s process of change. The impact of media coverage is complemented by continuing education for health professionals. Special efforts are still needed to improve access to the POLST Program for some rural, minority, and pediatric populations and for persons living at home with a diagnosis other than cancer. However, with enough time, a sustained effort, and a broad coalition of partners, profound change is possible.

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