

Chapter 49. Advance Planning For End-of-Life Care

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Background

Physicians and other health care workers have long struggled with decisions regarding care for patients at the end of life. An important component of this care involves assessing and understanding patient preferences for care through ongoing discussions with competent adult patients and/or their family members or surrogates. Advance care planning protects patient autonomy and helps to assure that their health and medical treatment wishes are implemented. Good communication at the end of life can also help patients achieve closure and meaning in the final days of their life.

Over the past 20 years, public consciousness regarding planning for end-of-life care has been raised through several seminal court cases, such as those involving Karen Ann Quinlan and Nancy Cruzan. These cases and the public interest they helped engender led to legislation promoting patients' rights to determine their care at the end of life. For example, Natural Death Acts (statutes passed by State legislatures that assert a person's right to make decisions regarding terminal care) have helped promote the use of living wills (described below).¹ In addition, in 1990 the Federal Patient Self-Determination Act (PSDA) was passed by Congress to encourage competent adults to complete advance directives. The PSDA requires hospitals, nursing homes, health maintenance organizations, and hospices that participate in Medicare and Medicaid to ask if patients have advance directives, to provide information about advance directives, and to incorporate advance directives into the medical record.²

Advance directives are any expression by a patient intended to guide care, should they lose their medical decision making capacity. Although both oral and written statements are valid, the added effort required to complete written statements gives them greater weight. In addition to their use when patients lose competence, advance directives also help patients consider the type of care they would want in the future, even if they retain decision making capacity. Advance directives have legal validity in almost every State.

There are 2 principal forms of written advance directives: living wills and durable powers of attorney for health care. A *living will* is a document that allows an individual to indicate the interventions he or she would want if he or she is terminally ill, comatose with no reasonable hope of regaining consciousness, or in a persistent vegetative state with no reasonable hope of regaining significant cognitive function. A *durable power of attorney for health care* (DPOA-HC) is a more comprehensive document that allows an individual to appoint a person to make health care decisions for him or her should he or she lose decision making capacity.

Prevalence and Severity of the Target Safety Problem

Respecting patient preferences regarding end-of-life care requires a well-coordinated approach. Problems can arise in both documenting patient preferences and ensuring that preferences are available and respected at the time they are needed. In addition, inadequate communication with patients can compromise the goal of respecting patient preferences for end-of-life care through a variety of mechanisms.

Failure to Document Preferences

The PSDA was a legislative solution (see Chapter 55) designed to increase rates of completed advance directives. Although there was initial hope that PSDA would markedly increase rates of advance directive documentation, by the early 1990s it was clear that the impact was small. At that time, a large multicenter randomized trial, the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), was undertaken to improve advance care planning. SUPPORT represents one of the largest and most comprehensive efforts to describe patient preferences in seriously ill patients, and to evaluate how effectively patient preferences are communicated. SUPPORT cost 28 million dollars and enrolled 9100 seriously ill patients. In SUPPORT, a trained nurse facilitator provided prognostic information to patients and medical staff, discussed patient preferences with patients and families, and facilitated communication between patients and physicians.

Neither the PSDA legislation nor the SUPPORT intervention had major impacts on the documentation of patients' preferences regarding end-of-life care. Teno et al reported on the documentation of advance directives at 3 points: before PSDA, after PSDA, and after the SUPPORT intervention. The percentage of patients with an advance directive was unchanged in all 3 groups, but documentation of those directives increased at each stage, from 6% to 35% to 78% in the SUPPORT intervention group. Despite this increase in documentation, only 12% of patients with an advance directive had talked with a physician when completing the document and only 25% of physicians were aware of their patients' advance directives.³ SUPPORT found that only 23% of seriously ill patients had talked to their doctors about their wishes concerning cardiopulmonary resuscitation (CPR) and that patient-physician discussions and decisions were uncommon even in seriously ill patients whose death was predictable.⁴ Another study that surveyed elders in community settings found that the vast majority (81%) stated their desire to discuss their preferences with their physicians if they were terminally ill, but only 11% had done so.⁵ As these studies demonstrate, patients often want to talk about death and dying but expect physicians to bring up the issues.⁶

Ensuring that Preferences are Available and Respected

Even when advance directives are prepared, studies show they often do not change interventions at the end of life.^{3,7} Advance directives are frequently not available, recognized or applied, nor do they help reduce hospital resource use. There are multiple reasons why advance directives may go unrecognized.⁸ Admitting clerks may fail to document or incorrectly document the status of a directive on admission to the hospital. Patients and families often do not inform the hospital physician or admitting clerk about their advance directives, or fail to bring documentation to the hospital.⁸ In one survey of 200 patients, only 18% had filled out an advance directive and of these, 50% had secured the only copy in a safety deposit box!⁹ A copy of the advance directive is often not transferred from the nursing home to the hospital on admission. In a study by Morrison, physicians documented advance directives or discussions with appointed proxies about treatment decisions in only 11% of admission notes.⁸

Although the goal of advance directives is to ensure that patients receive treatment that is consistent with their preferences, to date there is no evidence that documenting advance directives leads to this outcome. In SUPPORT, there was no evidence that increasing the rates of advance directives resulted in care more consistent with patients' preferences.¹⁰ This finding was concordant with a study of nursing home patients and their family members regarding preferences for aggressive treatment at the end of life. There, 25% of patients received care that

was inconsistent with their previously expressed wishes.¹¹ The problem may not be the substance of advance directives *per se*, but rather in the manner in which clinicians approach them. Physicians may be hesitant to initiate discussions of advance directives with patients, especially early in the course of an illness.¹²

Despite these shortcomings, advance directives remain the best available approach for helping patients plan future care. These discussions, difficult as they are, help ensure that patients receive care consistent with their values and goals, spare the patient inappropriate interventions, and help maintain dignity during the dying process.

Physician Communication

In order to improve the quality of end-of-life care, physicians need to effectively communicate with their patients and understand their preferences for care. Several studies have documented imperfections in physician-patient communication.^{13,14} Several studies have demonstrated that physicians often misunderstand or are unaware of their patients' preferences for care.^{15,16} Furthermore, physician prediction of patients' preferences for resuscitation are no better than random.^{3,14}

In summary, the published literature demonstrates significant problems in all areas crucial to advance care planning and ascertainment of patient preferences, transmission of information to appropriate care settings, and respecting those preferences. The provision of unwanted end-of-life care is an adverse event that can potentially be avoided by the implementation of effective patient safety practices.

Opportunities for Impact

Patients with chronic or life-limiting illnesses make up a large proportion of the adult primary care population. Almost three-quarters of the 2.3 million Americans that die each year are 65 years of age or older. By the year 2030, people older than 65 will comprise 20% of the total population (70 million people), compared with 13% in 1994. Today's average life expectancy is 75.5 years, and the leading causes of death are heart disease, cancer and stroke. Data from 1995 estimated that these causes accounted for 62% of all deaths and 67% of deaths for those age 65 and over.¹⁷ The overall picture is of an aging population, with many individuals living for several decades (often with chronic diseases) after the possibility of death becomes more than theoretical.¹⁸

SUPPORT documented serious problems with terminal care. Physicians did not implement patients' refusals of interventions. When patients wished to forgo CPR, a do not resuscitate order was never written in about 50% of cases.⁴ While 90% of Americans say they want to die at home, 4 out of 5 die in a hospital or other health care facility. The SUPPORT study showed that only 35% of the study patients had an advance directive. These patients had an approximate six month mortality rate of 50%.

Physicians and the public also commonly overestimate the effectiveness of CPR. In reality, in-hospital cardiac arrests have a survival rate of about 15%. For patients over 65 the survival rate is about 10-11%, and 3.5% for patients over age 85.¹⁹ Elderly nursing home patients with out-of-hospital arrest only have 1-2% survival.²⁰ Studies have shown that when patients are aware of the real survival rates for CPR, they are less likely to desire this intervention.

Evidence for Effectiveness of the Practice

Documenting Preferences and Ensuring that they are Available and Respected

A Physician Order form for Life-Sustaining Treatment (the POLST)

In the mid-1990s, a task force of ethicists and clinicians at the Oregon Health Sciences University developed a new Do Not Resuscitate (DNR) order form called POLST (Physician Orders for Life-Sustaining Treatment). POLST is a comprehensive two-page order form that documents a patient's preference for life-sustaining treatments. The form is designed to record a patient's wishes clearly and simply. The accompanying POLST wallet card is included as Figure 49.1; the complete POLST form and materials can be obtained from the Oregon Health Sciences University's Center for Ethics in Health Care (<http://www.ohsu.edu/ethics/polst.htm>).

Tolle et al examined the extent to which POLST ensured that nursing home residents' wishes were honored for DNR orders, and for hospital admission only if comfort measures failed. None of the 180 patients who completed POLST received CPR, ICU care, or ventilator support, and only 2% were hospitalized to extend life. The study subjects had low rates of transfer for aggressive life-extending treatments and high levels of comfort care.²¹

Since 1995, more than 220,000 copies of POLST have been distributed throughout the State. Data from 1999 suggest, albeit circumstantially, that this initiative may be working. In 1996, Oregon's in-hospital mortality rate was 31%, compared with the national average of 56%.²²

Lee et al studied the effectiveness of POLST in a Program of All-Inclusive Care for the Elderly (PACE) in Portland, Oregon. They retrospectively reviewed POLST instructions for each of the 58 participants and whether or not each of the treatments addressed by the POLST was administered in the final 2 weeks of life. The POLST specified DNR for 50 participants (93%); CPR use was consistent with these instructions for 49 participants (91%). The participants also designated the level of care they preferred as either comfort care, limited, advanced, or full intervention. Interventions administered were at the level specified in only 25 cases (46%), with less frequent deviations in antibiotic administration, administration of IV fluids, and placement of feeding tubes. The investigators concluded that the POLST effectively limits the use of some life-sustaining interventions, but that further investigation is needed into the factors that lead physicians to deviate from patients' stated preferences about other treatments.²³

Administrative Initiatives to Ascertain Preferences on Admission to Hospital or Nursing Home

In addition to POLST, some medical centers have developed admission order forms to document patient preferences regarding end of life. These forms require health care personnel to inquire about advance directives, resuscitation preferences, artificial fluids and nutrition, etc. This approach, promoted by the passage of the PSDA, may be effective in promoting provider-patient discussions about end-of-life wishes and prevent unwanted treatments. However, there are no data documenting the effectiveness of this strategy.

Ascertaining Preferences in the Outpatient Setting

As with other forms of computerized decision support (Chapter 53), computer-generated reminders for primary caregivers can increase the rates of discussion of advance directives and completion of advance directive forms among elderly outpatients with serious illnesses. Dexter et al performed a randomized, controlled trial to test the effectiveness of computerized reminders. The participants were 1009 patients and 147 primary care physicians in an outpatient setting. Physicians that received computer-generated reminders that recommended discussion of one or both of 2 types of advance directives were compared with physicians who received no reminders. Physicians who did not receive reminders (controls) discussed and completed advance directives in only 4% of the patients. On the other hand, physicians who received both types of reminders discussed (24%) and completed (15%) advance directives significantly more frequently.²⁴

The Portability of Advance Directives between Hospitals and Nursing Homes

Ghush et al retrospectively studied the relationship between inter-institutional communication and continuity of advance directives from hospital to nursing home settings. Having a hospital discussion about advance directives or having a hospital DNR order were associated with a higher rate of advance directive discussions in nursing homes. Hospital DNR orders were continued for 93% of patients discharged to the hospital-affiliated nursing home and 41% of patients discharged to the community nursing home. Specific communication of hospital DNR status to the receiving nursing homes was associated with better continuity of DNR orders. The authors concluded that completing advance directives before patients are discharged to nursing homes, communicating advance directives to the receiving home, and providing follow-up discussions at the nursing home might improve the continuity of advance directives between hospitals and nursing homes.²⁵

Practices to improve physician-patient communication and physician understanding of patient preferences

Training for Physicians

Physician education is an attractive way to improve end-of-life care. Physicians often do not communicate about advance care planning because many have not been taught the relevant communication skills and have learned them only through personal experience.²⁶ A study by Tulskey et al revealed that when physicians discussed end-of-life issues with their patients, they spoke twice as much as they listened and did not routinely explore patients' values.²⁶

Until recently, training for health care providers in palliative care and respecting patient preferences, and materials to support such training, were inadequate. For example, recent studies

have demonstrated that most medical and nursing textbooks insufficiently cover end-of-life care issues.²⁷ Increasingly, resources (including textbooks, palliative care journals or journal series,²⁸ Web sites and training programs) are filling this educational void. The American Medical Association has developed an extensive physician training program titled Education for Physicians on End-of-Life Care (EPEC).²⁹ This curriculum teaches fundamental skills in communication, ethical decision making, palliative care, pain and symptom management, and other end-of-life treatment issues.³⁰ The Robert Wood Johnson Foundation initiative, “Last Acts,” is another ambitious effort to educate both patients and providers.

Other educational training programs exist for physicians and students as well.³⁰ Physicians can receive formal training by attending conferences on decisions near the end of life, case management meetings regarding individual patients, and seminars on communication skills with individual feedback to physicians on their performance.³¹ Physicians with expertise in this area often conduct seminars to educate physicians. Buckman and Lo have developed guides for specific end-of-life discussions, such as breaking bad news and the act of active listening and empathy.^{32, 33}

As attractive as these educational programs are, none have been studied for their impact on changing practice or outcomes. Although common sense might tell us that such programs are likely to be effective, the generally unimpressive relationship between professional education and outcomes or process change (Chapter 54) provides grist for uncertainty pending formal effectiveness studies.

Palliative Care Services

Specialized palliative care programs have become increasingly common in the health care system. Physicians and other health care providers, including nurses, social workers, chaplains, and others are available to coordinate care and provide consultation for terminally ill patients in hospices, hospitals, nursing homes or patient’s homes. The palliative care service also plays an important role in fostering communication among providers, patients, and families. Data regarding effectiveness are lacking.

Hospitalist Systems

Hospitalist physicians may improve end-of-life care in hospitals. Hospitalists, by virtue of their large inpatient volumes, should become increasingly facile with ascertaining patient preferences regarding end-of-life care. Hospitalists have a unique opportunity to approach patients, since an admission generally signals either a worsening of the patient’s current condition or a new diagnosis. The hospitalist may have more time to spend with patients and is available over consecutive hospital days to answer any questions. A routine discussion of advance directives by hospitalists can help improve the quality and efficiency of patient care.³⁴ On the other hand, patients may have a long-standing trusting relationship with their primary care physicians, and may have expressed their wishes to this physician prior to hospitalization. This possibility highlights the importance of hospitalist-primary care provider communication, particularly concerning end-of-life issues.³⁴

One retrospective chart review study of 148 patients dying at a community teaching hospital has examined the impact of hospitalists on end-of-life care. In this study, patients cared for by hospitalists were significantly more likely to have had a documented family meeting (91% vs. 63% for patients of community-based primary physicians). About two-thirds of patients in both groups requested limitations in the level of care by the time of death. Of these, patients of hospitalists were significantly less likely to have documented pain, dyspnea, or anxiety in the 48

hours prior to death (57% vs. 75%). Whether these differences reflect differences in the quality of care, the completeness of documentation, or underlying patient differences requires further study.³⁵ Although the hospitalist movement holds promise for improving end-of-life discussions, more research is needed to determine whether this promise will be met.

End-of-Life Education for the Public

Extensive public awareness and educational programs are necessary to create a foundation for successful end-of-life conversations in patients with advanced illness. Broadcasts, such as the PBS-Bill Moyers special “On Our Own Terms,” may help the public appreciate the experience of terminal illness, and the complex choices that are faced. Such presentations may encourage viewers to discuss how they might manage a similar situation, and explore their own fears and concerns about dying. There are no data regarding the effectiveness of public education to improve advance care planning.

Other Locally Successful Advance Care Planning Programs

Individual programs to implement patient preferences have emerged around the country. Limited data suggest that they may be effective, and bear further examination as to their portability to other programs and settings and their durability over time.

- “Respecting Your Choices” Program

Gundersen Lutheran Medical Center in La Crosse, Wisconsin has worked on community-wide programs to improve advance care planning with an initiative called “Respecting Your Choices.” This program used patient and family education, community outreach, education for non-medical professionals, standard training sessions, and standard methods for documenting and tracking advance directives. Hammes et al reported that 85% of patients in the intervention group had written advance directives at death, executed on average 1.2 years before death. Of these directives, 95% were in the medical record. Virtually all patients (95%) reported that the interview process was meaningful. The patients felt that they benefited from improved communication with loved ones and with health care providers.³⁶

- Dayton VA Initiative

The Dayton (Ohio) VA Medical Center aimed to increase the number of veterans who participated in advance care planning. VA patients and their families received a patient education booklet and a video on advance care planning. The VA also developed discussion guidelines for providers, initiated an advance care planning clinic, and initiated a bereavement support group. In a 12-week period, advance care planning discussions and follow-up increased from about 15% percent of charts to almost 90%.³⁷

- “Let Me Decide” Program

Molloy et al examined patient satisfaction with decision making and health care costs after systematically implementing an advance directive program in nursing homes. The “Let Me Decide” program included educating staff in local hospitals and nursing homes, residents, and families about advance directives and offering competent residents or next-of-kin of mentally incompetent residents an advance directive. The researchers reported that systematic implementation of this program reduced hospitalizations and aggressive care for nursing home patients who did not want that level of intervention. It also reduced utilization of health care services without affecting satisfaction or mortality.³⁸

Costs and Implementation

Estimating the cost of ascertaining and respecting patient preferences is difficult since improvements in this area may require major changes in the structure of the health care system. Institutional barriers, the culture of medicine, patient attitudes, time constraints physicians face with office visits may all play a role in implementation and may inhibit change.²⁶ Barriers to implementation include complacency on the part of the physician and patient, fear of political controversy, diffused responsibility, and absence (or perverse) financial incentives for providers and institutions. The surprising ineffectiveness of the SUPPORT intervention, which cost over 28 million dollars, demonstrates how difficult it is to make major improvements in this area. Nevertheless, improving our ability to respect patient preferences is valuable in its own right and may ultimately prove to be cost-effective, since some patients will choose to forego high technology and expensive care at the end of life.

Medical care at the end of life consumes 10% to 12% of the total health care budget. An estimated 40% of the Medicare budget is spent during the last 30 days of life.³⁹ Some have posited that increased use of hospice and advance directives and lower use of high-technology interventions for terminally ill patients will produce significant cost savings. However, the studies on cost savings from hospice and advance directives are not definitive. The 3 randomized trials of hospice and advance directives use show no overall savings, but the authors of a review suggest that the studies were either too small for confidence in their negative results or their intervention and cost accounting are flawed.⁴⁰ In the absence of a definitive study, the existing data suggest that hospice and advance directives can save between 25% and 40% of health care costs during the last month of life, but far less (and perhaps nothing) in the 3-12 months before death. Although, these savings are less than most people anticipate, they do indicate that hospice and advance directives should be encouraged because they certainly do not cost more and they provide a means for patients to exercise their autonomy over end-of-life decisions.⁴⁰ Finally, several of the promising interventions described above (eg, the POLST intervention), are relatively inexpensive. For example, 500 POLST forms can be ordered from Oregon Health Science University's Web site⁴¹ for less than \$100, although the cost of implementing the POLST program is unknown.

Comment

Preventing unwanted aggressive care at the end of life requires active communication between provider and patient, and effective strategies to transfer information regarding preferences seamlessly across care venues. The dominant strategy to improve care in this area over the past 20 years has been the promotion of advance directives. Although the enthusiasm for advance directives has not been matched by evidence of their effectiveness, SUPPORT and other studies have renewed public concern and prompted providers and policy makers to reexamine advance care planning and strive to improve it. Although we have found evidence of several potentially promising strategies (perhaps the most promising of which is the POLST form), the inevitability of death and the importance patients place on improving end-of-life care point strongly to the need for further research in this area.

Figure 49.1. POLST Wallet Card instructions

<p style="text-align: center;">POLST WALLET CARD INSTRUCTIONS</p> <p>This is an identification wallet card for the Physician Orders for Life-Sustaining Treatment (POLST) document. This card is not a substitute for a completed POLST document. It provides a summary of the POLST document and is expected to be honored by care providers.</p> <p>The POLST document and wallet card are completed by the physician. The physician must sign both the POLST document and the wallet card to make the wallet card valid.</p> <p style="text-align: right; font-size: small;">Instructions continued on other side.</p> <hr style="border-top: 1px dashed black;"/> <p>Physician Orders for Life-Sustaining Treatment</p> <p>Name: _____</p> <p>Resuscitation (Patient has no pulse <u>and</u> is not breathing):</p> <ul style="list-style-type: none"> • <u>R</u>esuscitate • <u>D</u>o <u>N</u>ot <u>R</u>esuscitate (DNR) <p>Medical Interventions (has pulse <u>and/or</u> is breathing):</p> <ul style="list-style-type: none"> • Comfort Measures Only • Limited Interventions • Advanced Interventions • Full Treatment/Resuscitation <p>Antibiotics:</p> <ul style="list-style-type: none"> • No antibiotics except if needed for comfort • No invasive (IM/IV) antibiotics • Full Treatment <p style="text-align: right; font-size: small;">Instructions continued on other side.</p>	<p style="font-size: small;">...continued from other side</p> <p>It is recommended that the completed wallet card be laminated in plastic for durability and to prevent alteration. An existing card should be destroyed if the POLST document is changed.</p> <p>A new wallet card can be completed to match the new physician orders.</p> <p style="text-align: center;">** CENTER FOR ETHICS IN HEALTH CARE</p> <p style="text-align: center;">Oregon Health Sciences University</p> <p style="text-align: center;">3181 SW Sam Jackson Park Rd., UHN-86</p> <p style="text-align: center;">Portland, Oregon 97201-3098</p> <p style="text-align: center;">(503) 494-4466</p> <hr style="border-top: 1px dashed black;"/> <p>Artificially Administered Fluids and Nutrition:</p> <ul style="list-style-type: none"> • No feeding tube/IV fluids • Full Treatment • No long term feeding tube/IV fluids <p>Discussed with:</p> <ul style="list-style-type: none"> • Patient • Health Care Representative • Court-appointed Guardian • Spouse • Other <p>I have completed the following forms:</p> <ul style="list-style-type: none"> • Advance Directive • Court-appointed Guardian <p>_____</p> <p>Print name of Physician Phone</p> <p>_____</p> <p>Signature of Physician Date</p> <p style="font-size: x-small;">** Center for Ethics in Health Care Developed in conformance with ORS 127.505 et seq.</p>
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