Integrating POLST into Palliative Care Guidelines: A Paradigm Shift in Advance Care Planning in Oncology

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After several decades of steady increase, the cancer death rate declined slightly from the early 1990s through 2002. In 1997, 65% of adults who had been diagnosed with cancer at all sites had survived for at least 5 years. Patients presenting with late-stage disease at diagnosis have limited survival, and more than 85% of patients with advanced cancer requiring systemic chemotherapy die of their disease.

Humane care for dying patients is a social obligation that is not adequately met. Too often, death is considered a medical failure rather than the inevitable final chapter of life. Therefore, many people approach death fearing abandonment during a time of need, profound suffering of self and family, and a protracted, overtreated ending. Their fears are not unsubstantiated, because life-sustaining procedures are frequently administered in direct contradiction to patient wishes.

Despite the growing proclivity to administer life-sustaining treatments, research indicates that the increased interventions have not reduced mortality rates. In many cases, life-sustaining treatments only prolong the dying process. Reducing unwanted, unnecessary, and futile interventions at the end of life will realign the intensity of care with patient preferences without adversely impacting mortality rates. Improvements in patient and family satisfaction, provider satisfaction, risk management, and medical cost containment will also result.

Using tools such as advance directives and the Physician Orders for Life-Sustaining Treatment (POLST) Paradigm Program, while simultaneously promoting palliative care, helps accomplish these improvements. Advance directives more accurately convey end-of-life preferences that are more likely to be followed by medical professionals than traditional advance directives alone. (JNCCN 2006;4:819–829)
and POLST aid the effective communication of personal wishes, facilitate patient-centered care, and provide a framework for discussing end-of-life care wishes.

The NCCN Palliative Care Clinical Practice Guidelines in Oncology were developed to facilitate the appropriate integration of palliative care into anti-cancer therapy, with the goal of providing the best quality of life possible to every patient with cancer. This includes providing high-quality end-of-life care. From the patient perspective, Singer et al. identified and described quality end-of-life care as receiving adequate pain and symptom management, avoiding inappropriate prolongation of dying, achieving a sense of control, relieving the burden on loved ones, and strengthening the relationship with loved ones. McGraw et al. added that this includes that health care professionals respect the uniqueness of individuals, provide an appropriate environment, address spiritual issues, recognize cultural diversity, and establish effective communication with the dying person and family. Effective advance care planning based on patient-centered goals of care is critical in achieving quality end-of-life care and has been included in the algorithm for the NCCN Palliative Care Guidelines. All individuals should be screened routinely at initial consultation for traditional advance directives.

In 1991, the federal government passed the Patient Self-Determination Act (PSDA), guaranteeing individuals the right to make health care decisions and indicate preferences about life-sustaining treatments. The PSDA requires any health care facility receiving federal funding to inform patients about advance directives. More importantly, patients should be counseled about the importance of completed advance directives. Studies have shown that physician counseling markedly increases the completion rate of advance directives.

Unfortunately, advance directives have their own issues and are not widely used. The advance directive completion rate in the United States has not significantly increased since the PSDA passed in 1991. That year, 75% of Americans approved of a living will, yet only 20% had some form of advance directive. A 2002 study showed no improvement in the advance care directives completion rate, which remained at 15% to 20%. Completion rates were no better for individuals at higher risk. Only 20% of nursing home residents had any form of advance directive. A November 2005 poll by the Pew Research Center for the People and the Press showed that Americans are increasingly likely to plan for future health care. A poll performed after the Terri Schiavo case unfolded indicated that 29% of Americans have advance directives.

Meanwhile, many Americans die in pain, hospice care remains underused, and patients continue to suffer needlessly at the end of life. Research suggests the need for a more comprehensive, system-based approach to ensure effective advance care planning and end-of-life decision-making. The POLST Paradigm Program presents such an approach, particularly for patients with advanced chronic illness who have a life expectancy of less than 1 year.

Benefits of Advance Care Planning
Anyone can face sudden, unexpected, life-limiting illness or injury. Thus, advance care planning is appropriate for all adults aged 18 years and older, not only those with life-limiting illness (Figure 1). The process determines future medical care preferences if decisional capacity is lost, helps the patient prepare for death, and addresses surrogate decision-making and care end-of-life care preferences. Advance care planning focuses on conversation, selection of a trusted surrogate to represent the patient when the capacity to represent oneself is lost, and clarification.
of values and beliefs. The result is the completion of accessible legal documents and a commitment to periodic reassessment. Advance care planning helps patients maintain control and achieve peace of mind and is an important step in assuring that wishes are honored. Absence of legal documents can result in situations illustrated by Karen Ann Quinlan, Nancy Cruzan, and Terri Schiavo.

Advance directives can impact patients’ satisfaction with their health care providers. One study determined that the strongest predictor of satisfaction with care was the presence of advance directive discussions. Elderly patients with chronic illnesses who discussed advance directives with their primary care physicians showed significantly greater satisfaction with their care than those that did not have a discussion about advance directives.16

Health Care Professional Barriers to Advance Care Planning Discussions

A self-assessment of potential barriers to initiating conversations will help health care professionals overcome them. Barriers that keep health care professionals from engaging in the process should be considered. Health care professionals should ask themselves the following questions:

- Are you uncomfortable discussing death?
- Do you believe that “accepting mortality” is “giving up hope”?
- Are you afraid that a discussion about death will “make it happen”?
- Are you unwilling or unsure how to broach the topic?
- Do you understand the benefits of advance directives and advance care planning?
- Are you able to find reliable resources related to advance directives and advance care planning?
- Have you completed advance directives and shared your wishes with your family, your physician, and trusted individuals?

Conversations with the Patient/Family Unit

From the patient’s perspective, advance care planning is about not only retaining autonomy and exercising control but also building or maintaining personal relationships and relieving burdens placed on others.17

Advance care planning extends beyond the physician–patient relationship. Counseling should promote and facilitate conversations within the patient/family unit and with close loved ones. An integrative approach to advance care planning can be provided by physicians, nurses, social workers, or patient advocates in the ambulatory setting.18 Families who withdraw life-sustaining treatments from loved ones experience significantly higher stress for longer periods when advance directives are absent.19 This stress is lower when verbal discussions direct family decision-making, and lowest when written directives are completed.19 This finding is significant when considering that one study showed that only 5% of 2000 patients in the intensive care unit (ICU) had decisional capacity when the decision was made to withdraw or withhold life-sustaining treatments.19

Documenting the patient’s and/or surrogate’s preferences while the patient has capacity will improve the poor concordance often seen between the patients’ preferences and the treatments that their physicians and spouses believe they want. Discussion of preferences for goals of care, treatment options, and setting of care should occur with the patient and the family unit designated by the patient.

Cultural factors strongly influence patient views about serious illness and may impact the advance care planning process. Health care professionals must appreciate and respect cultural values and beliefs. Recognizing that variation exists within a culture is equally important. The best method for understanding these cultural factors is to simply ask the patient.

Assessing Behavioral Readiness to Complete an Advance Directive

Behavior is too complex to systematically and consistently respond to one type of intervention. After years of clinical observation and extensive research, Prochaska et al.20–22 formalized the transtheoretical model of change, which provides a framework for behavior change that is easily applied in clinical or real-life situations (i.e., the behavioral readiness to change outlined in Figure 2). Successful self-changers follow an unwavering sequence of activities and attitudes before finally changing an undesirable lifestyle. Using the model’s central “stages of change” construct, discussion and intervention can be linked with behavioral readiness to complete an advance directive, which therefore can be more focused. To be
effective, counseling should include key elements of the advance care planning process and be individualized according to the patient’s current condition and behavioral readiness to complete an advance directive.\textsuperscript{20} Using this approach to behavioral change and the stages of change, the Health Care Proxy Readiness Survey (Figure 3) was developed to assess the success of Community Conversations on Compassionate Care, a community educational workshop on advance care planning.\textsuperscript{23}

In stage 1 (precontemplation), the patient sees no need to complete an advance directive and the intervention is focused on providing educational information about advance directives. In stage 2 (contemplation), the patient sees the need to complete an advance directive but has barriers or reasons why the advance directive is not completed. Discussion and intervention should identify patient barriers and focus on removing them. Barriers may include claims such as:

- I do not know enough about it; I do not know what it is.
- It is not important.
- I do not want to think about it; I do not want to discuss it.
- I do not have enough time.
- I do not know how to bring up the subject with my family.
- It is too difficult.

In stage 3 (preparation), the patient is ready to complete an advance directive or has already begun, and therefore the primary intervention should focus on motivating the patient. In stage 4 (action), the patient has completed an advance directive that reflects their wishes. In addition to obtaining a copy of the completed advance directives, patient values and preferences should be elicited, family discussion encouraged, and appropriateness of designated health care agent assessed. Stage 5 (maintenance) reflects the need to review and update advance directives and is discussed later. The algorithm in Figure 4 shows how behavioral readiness and advance care planning discussions can be integrated in the NCCN palliative care guidelines for patients with a life expectancy of greater than 1 year.

### Eliciting Personal Values, Beliefs, and Goals for Care

Physicians are frequently unaware of patient preferences for end-of-life care. The care provided to patients is often inconsistent with their preferences and often associated with factors other than preferences or prognoses.\textsuperscript{24} Patient preferences may not be communicated to family. Several tools are available to help patients explore their feelings about end-of-life care, such as the questionnaire shown in Figure 5. Discussion of preferences for goals of care, treatment options, and setting of care should occur with the patient and the family unit designated by the patient.
Designating a Health Care Agent

Designating an appropriate health care agent or surrogate decision-maker will help prevent the uncertainties that may arise during decision-making at critical points in the course of providing care. Patients benefit from counseling when they choose a health care agent. This agent must:

- Meet legal criteria (i.e., be a competent adult, at least 18 years old)
- Be willing to speak on behalf of the individual
- Be willing to act on the individual’s wishes
- Be willing to separate own feelings from those of the individual
- Live close by or be willing to come when needed
- Know the individual well
- Understand what is important to the individual
- Be willing to talk to the individual about sensitive wishes
- Be willing to listen to the individual’s wishes
- Be able to work with those providing care to carry out the individual’s wishes
- Be available in the future
- Be able to handle potential conflicts between family and friends
- Be able to handle responsibility

Practical Issues

Accuracy of Completed Document

Once completed, the advance directive documents should be reviewed by the physician to ensure that they are completed accurately, comply with state law, and are consistent with the patient’s expressed wishes.

Figure 4 Advance care planning for patients with a life expectancy of greater than 1 year.

Figure 5 Exploratory questions to elicit patient feelings about end-of-life care. The information contained within this page is from © EPEC Project, The Robert Wood Johnson Foundation, 1999.
Accessibility

The accessibility of completed advance directives is an important measurable outcome of the process but should not be viewed as a substitute for conversations. Easy access to completed legal documents prevents delayed decision-making and helps prevent undesirable care decisions.

Periodic Review and Update

Advance directives require ongoing reassessment and periodic updates. After major life events such as divorce, birth of a child, or death of a spouse, the patient may wish or need to choose a new health care agent. Goals of care and preferences may change as chronic illness progresses and after patients undergo complicated life-sustaining treatments.

Although traditional advance directives convey a patient’s treatment preferences when that patient is incapacitated, all possible clinical scenarios and potential treatment options cannot be included in an advance directive. Therefore, patient preferences for goals of care, treatment options, and setting of care should be reviewed and documented at first assessment and at frequent intervals as conditions change.

Capacity Assessment

Advances in health care and changing demographics have led to an aging population that is facing increasingly complex end-of-life care. The incidence of cancer and cognitive impairment both increase with age. The NCCN Senior Adult Oncology Guidelines recommend assessing the geriatric patient’s ability to make decisions but do not include pertinent recommendations for capacity assessment.

Capacity is the ability to take in information, understand its meaning, and make an informed decision based on the information. Intact capacity permits functional independence. Capacity requires a cluster of mental skills people use in everyday life, including memory, logic, the ability to calculate, and the flexibility to turn attention from one task to another. Medical determination of capacity is often difficult to perform, and no standard tool is available for this assessment. It is a complex process that cannot be determined simply by using the Mini-Mental State Examination (MMSE). Capacity assessment should involve a detailed history from the patient, a collateral history from family, and a focused physical examination that includes cognitive, function, and mood screens and appropriate testing to exclude reversible conditions. Capacity requirements vary by task. For example, the capacity to choose a trusted individual as an appropriate health care agent differs from the capacity to agree to a medical procedure or treatment.

From a legal perspective, capacity depends on the ability to understand the act or transaction, understand the consequences of taking or not taking action, understand the consequences of making or not making the transaction, understand and weigh choices, and make and commit to a decision.

Establishing Plans of Care for Patients Who Lack Decision-Making Capacity

Advance care planning for patients lacking decision-making capacity requires special consideration to ensure maximal patient participation with appropriate surrogate involvement. The most common pitfalls the physician encounters in establishing plans of care for patients who lack decision-making capacity include the physician’s failure to:

- Use effective communication skills
- Recognize the patient’s values and goals of care
- Acknowledge that goals guide care and the choice of interventions
- Reach a mutual understanding of the patient’s condition and prognosis with the family
- Offer the choice between life prolongation and quality of life, instead of offering the choice between treatment and no treatment
- Address the full range of end-of-life decisions, from do-not-resuscitate orders to exclusive palliative care
- Provide evidence of previous repeated oral expression of wishes, instead of applying a literal interpretation of an isolated, out-of-context patient statement made earlier in life
- Apply the principle of substituted judgment, in which the surrogate attempts to establish as accurately as possible what decision the patient would have made if that patient were competent to do so. This standard seeks to preserve the patient’s right of self-determination by placing the patient’s own preferences at the center of deliberation, while recognizing that it is the exception rather than the rule that the patient has articulated his or her preferences in advance.
**POLST and Palliative Care Guidelines**

**Figure 6** Sample Physician Orders for Life-Sustaining Treatment (POLST) form. © Center for Ethics in Health Care, Oregon Health & Sciences University; printed with permission. Second page and additional samples are available at www.polst.org.
Life-Sustaining Treatments and Functional Health Illiteracy

Physicians tend to overestimate the likelihood of survival of in-hospital cardiopulmonary arrests. Literature reports an average survival rate of 15%. At least 44% of the survivors have a significant decline in functional status at discharge. Chronic illness, more than age, determines prognosis in elderly patients. Those with chronic illness have an average survival rate of less than 5%. For those with advanced illness, survival rates are often less than 1%. Bedfast patients with metastatic cancer who spend 50% of their time in bed have a survival rate of 0% to 3%.

Improved survival rates with good functional recovery are reported with cardiopulmonary resuscitation (CPR) lasting shorter than 5 minutes and CPR occurring in the ICU. Poor outcomes at all sites of care are associated with unwitnessed arrest, asystole, electrical–mechanical dissociation, more than 15 minutes of CPR, metastatic cancer, multiple comorbidities, and sepsis. Patients and families have significant functional health illiteracy about life-sustaining treatment, adding to the burden of medical decision-making. Studies have shown that physicians speak to patients about CPR 75% of the time, often using medical jargon. Further studies show that after discussions related to CPR, 66% of individuals did not know that mechanical ventilation is often needed after resuscitation, 37% thought ventilated patients could talk, and 20% thought ventilators were oxygen tanks.

Experts speculate that survival rate misconceptions are further complicated by the fact that 67% of resuscitations are successful on television. Actually, attempts to educate patients are successful. In one study of 371 individuals older than 60 years, 41% initially said they would want CPR; however, after learning the probability of survival, only 22% said they would want it.

POLST Paradigm Program

Because predicting and outlining guidance for all possible scenarios is difficult, advance directives are rarely sufficiently precise to dictate patient preferences in specific situations as a disease progresses. Thus, for a patient with advanced metastatic cancer, converting patient-centered treatment goals into actionable medical orders while the patient retains capacity is a more effective means of communicating patient preferences and ensuring these preferences are honored than are traditional advance directives. This is true for any patient who may die in the following year, including patients with end-stage cardiac or pulmonary disease or advanced dementia.

Issues surrounding medical decision-making for patients increasingly challenge physicians. Many studies have shown that most patients either do not have advance directives or, if they do, these directives do not adequately provide health care professionals with explicit instructions for making critical decisions. As a result, health care professionals may withhold or initiate treatments that are either not medically indicated or not desired by the patient. The POLST Paradigm Program is a goal-based advance care planning program that was developed in Oregon for individuals with advanced chronic progressive illness and anyone interested in further defining their care wishes. The goal of POLST is to express patients’ treatment goals as actionable medical orders that are based on communication with patients and/or surrogates, using the informed consent process. POLST brings together...
multiple professionals from across the health care system to meet the goals of patients. The process results in completion of the POLST form (Figure 6), which may be used to either limit medical interventions or clarify a request for all medically indicated treatments, including CPR. The form provides explicit directions regarding resuscitation if the patient is pulseless and apneic. It also includes directions regarding other types of intervention that the patient may or may not want, such as decisions about transport, ICU care, antibiotics, and artificial nutrition. The form accompanies the patient and is transferable and applicable across care settings (e.g., long-term care, emergency medical service, hospital). It is uniquely identifiable, standardized, and a uniform color within a state or region. The process includes training health care professionals across the continuum of care about the goals of the program, implementation of the program, use of the form, and a plan for ongoing monitoring of the program.

Research has shown that the POLST program results in a higher degree of concordance with a resident’s expressed advance directives for health care. A decade of research in Oregon has proved that the POLST program more accurately conveys end-of-life preferences that are more likely to be followed by medical professionals than traditional advance directives alone.39–42

Incorporating POLST into the advance care planning process for patients with a potential life expectancy of less than 1 year is illustrated in the algorithm in Figure 7. Further information on the POLST Paradigm Program and other states that are replicating this goal-based paradigm can be found at www.polst.org. States with endorsed programs may
vary in name and format but share essential core elements. For example, in New York, the POLST Paradigm Program is called the Medical Orders for Life-Sustaining Treatment (MOLST). Figure 8 outlines the 8-step protocol for the MOLST program. Further information about MOLST can be found at www.compassionandsupport.org.

**Conclusions**

Integrating palliative care and life-prolonging interventions present unique challenges for oncology care. With increasing attention on quality-of-life issues in oncology, palliative care has developed into an integral part of comprehensive cancer care. Palliative care focuses on holistic care with an emphasis on pain and symptom management and advance care planning, which is an essential process that should begin in the early phase of care. Discussions and interventions can be more effective if linked with the stages of change and the patient’s readiness to complete an advance directive. For a patient with advanced metastatic cancer or who might die in the next year, patient-centered treatment goals should be converted into actionable medical orders while the patient retains capacity. The POLST Paradigm Program provides an effective means of communicating and ensuring patient preferences are honored.

**References**


### POLST and Palliative Care Guidelines

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