Building on Individual, State, and Federal Initiatives for Advance Care Planning, an Integral Component of Palliative and End-of-Life Cancer Care

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Abstract

Federal and state provisions for advance care planning—the process by which patients, families, and medical professionals plan for future and, in particular, end-of-life care—continue to receive attention. Such planning remains an integral component of palliative care, complementing the recognition and treatment of pain and other symptoms that patients with advanced malignancies and their families encounter. Historically, advance care planning interventions (particularly those involving advance directives) have been unable to consistently demonstrate positive outcomes for patients with life-threatening illnesses. However, more recent literature, including that on patients with cancer, illustrates that both patients and caregivers report improved quality of life and less distress after discussions with their health care teams about end-of-life care. Herein, we discuss recent federal and state public policy that focuses on advance care planning, suggesting the promise for care delivery improvements and the means by which existing barriers might be surmounted. These care delivery issues apply to several disease states but are particularly pertinent to the adult oncology setting.

Introduction

Of the several ongoing debates surrounding President Obama's Patient Protection and Affordable Care Act (PPACA), perhaps none sparked more intensely politicized rhetoric and media coverage than former Alaskan governor Sarah Palin's classification of reimbursing practitioners for voluntary discussions with patients every 5 years regarding desired care in case of deteriorating health as tantamount to "death paneling." Although deemed by many in health care and the public a gross misrepresentation, the comment served, perhaps ironically, to catalyze a string of community, practice, legislative, and research initiatives on advance care planning, spanning local to national levels. The means by which such care-coordination logistics will unfold remains unclear. However, society's growing recognition of the salience of the topic has increased the importance of addressing these questions.

Advance care planning can take many forms, from the designation of a health care proxy and drafting of a living will to the many discussions with physicians aimed at sensitively educating patients, elucidating goals for future care, and sometimes, formulating advance directives about certain life-sustaining therapies (such as cardiopulmonary resuscitation, mechanical ventilation, parenteral nutrition, and hemodialysis).[1]

Case Example

An outpatient encounter with a 68-year-old woman with newly diagnosed pancreatic cancer recently brought to mind the myriad difficulties in health care communication alongside the vital role it plays in patient care and advance care planning. On this particular day, tension seemed to follow me (A.S.E.) into the room, an all too familiar experience for medical oncologists embarking on relationships with patients and families seeking opinions about new cancer diagnoses. Having regularly seen patients with advanced pancreatic cancer—a justifiably daunting illness for patients, loved ones, and clinicians alike—I had grown accustomed to introducing myself and my role, jointly arriving at mutual goals for the encounter, and beginning a review of the medical details leading to the diagnosis. Often before the transition to this last step, however, intense emotions brew, in various forms, in the patient or family, and this day proved no exception. Although the patient remained remarkably calm, her husband anxiously confided, "I've been so scared ever since we were told that my wife has cancer."

This represented an opportunity to respond to their emotional disclosure, a difficult task for which our fellowship program recently had provided group-based communication skills training. I exercised a mnemonic-based tool we had practiced in class and which I had later read about: **NURSE**.[2] **N**aming the emotion, I proceeded to express an **U**nderstanding of the husband's fear, and then demonstrated **R**espect for how well they seemed to be coping during this difficult time. I conveyed our intent to **S**upport them in their journey, and then asked him to **E**xpand on his statement.

I was concerned that this seemingly formulaic approach might appear disingenuous and consume precious time, leading us astray from the medical details. Rather, it felt natural, took only a few minutes, and helped the patient and family feel more relaxed, facilitating a productive discourse about the disease and what treatment would entail. It was clear that we were now all on the same page, a situation at which it is often difficult to arrive. After reviewing the history and examining the patient, we discussed her pancreatic cancer—with equal efforts at sensitivity and clarity—and that this was a treatable illness but, unfortunately, incurable and with serious prognostic implications. The patient's relatively high degree of physical wellness, knowledge, and family support (which included her assignment of her husband as health care proxy), as well as the freshness of my communication skills training, made this easier than a number of similarly challenging encounters I have struggled through in the past. The meeting exemplified the therapeutic import of not only providing patients with the most sophisticated treatments but also engaging them in informative, tailored discussions regarding overall goals of care. Furthermore, the discourse suggests that advance care planning entails not only medical documention such as living wills and proxy assignments but more importantly, the process by which physicians skillfully develop a continued understanding of the patient and his or her individual values.

Barriers to Optimal Advance Care Planning and Patient-Physician Communication

Although the encounter described marked a successful beginning, various factors, from time constraints and language barriers to literacy and knowledge shortcomings and psychologic difficulties, complicate consultations with many patients and families. Even when communication successfully results in the completion of advance directives, the documentation and application of such directives can be hampered by ever-changing patient disease courses and care settings. Such barriers have been well described in the literature[3,4] and represent ongoing unmet patient needs deserving of public attention, research efforts, and policy change. Although the inclusion in the PPACA of reimbursing advance care planning conversations initially generated hope for proponents, the provision was struck from the legislation in a matter of days after its official inception in January 2011.[5]

Policy Initiatives Aimed at Readdressing Advance Care Planning

Patient and family empowerment has figured prominently in the current sea change in US health care. April 16, 2011, marked the fourth annual National Healthcare Decisions Day.[6] Moreover, beginning September 2011, Joint Commission–accredited hospitals were deemed eligible to receive advanced certification in palliative care, which includes "a special focus on patient and family engagement; processes which support the coordination of care and communication . . . and the use of evidence-based guidelines . . ."[7]

In addition to resurgent national attention, statewide initiatives, including those in New York and Massachusetts, have arisen, reigniting enthusiasm for the advance care planning movement as well as questions of implementation. Recently, Massachusetts government officials announced plans to introduce legislation broadening Medicaid coverage to hospice care. Such reform was proposed[8] by a state committee of public policy figures and end-of-life medical specialists, which also supports the use of Medical Orders for Life-Sustaining Treatment, detailed advance directive forms that in pilot testing have aimed to demonstrate portability across different health care settings and disease processes. Medical Orders for Life-Sustaining Treatment represent a key initiative aimed at improving the effectiveness of advance directives.[9] A similar form, Physician Orders for Life-Sustaining Treatment, proved effective in a 1-year multicentered prospective study of 180 nursing home residents in leading to care consistent with indicated wishes about life-sustaining therapies: All 180 preferences for do-not-resuscitate orders were honored, and only four patients (0.02%) were hospitalized (against originally designated wishes) for the express purpose of extending life.[10]

In New York, the Family Health Care Decisions Act,[11] which was originally proposed in the early 1990s, was officially signed into law by former governor David Patterson on March 16, 2010. Key provisions were made effective June 1, 2010, codifying that "a surrogate is selected and empowered to make health care decisions for patients who lack capacity to make their own health care decisions and who have not otherwise appointed an agent to make health care decisions pursuant to . . . the public health law or provided clear and convincing evidence of their treatment wishes." Shortly thereafter, the Palliative Care Information Act (PCIA)[12] was enacted into law in August 2010 and requires all New York state physicians and nurse practitioners to provide information to patients with life expectancies of less than 6 months on available treatments and interdisciplinary services aimed at optimizing end-of-life experiences and relief of pain and associated symptoms. The law intends to "ensure that patients are fully informed of the options available to them . . . so that they are empowered to make choices consistent with their goals for care, and wishes and beliefs." Although skeptics have branded the legislation "adversarial"[13(p1885)] and problematic from enforcement and logistical standpoints, PCIA represents scaffolding from which additional advance care planning improvements can be built. The Family Health Care Decisions Act and PCIA empower patients on both individual and surrogate levels and thus are complementary legislative initiatives that serve to uphold patient autonomy and support optimal care delivery.

Benefits of Advance Care Planning

Although the strategies by which to obey health care law have yet to be elucidated, past research on the feasibility and benefits of expanded communication is reassuring. A growing body of literature has demonstrated that contrary to previous concerns, patients with serious illness do not lose hope,[14] incur lasting psychologic harm,[15] or have worse survival[16] after end-of-life discussions and honest disclosure of poor prognoses. Furthermore, although patients might understandably not want to have such conversations, if necessary, the majority would prefer that such discourse takes place with their primary medical provider.[17] The palatability of these discussions for patients is important to note in the face of the caregiver burden that often results when patients lack capacity, particularly in settings in which patient values are not known. Of the 3,746 patients in the Health and Retirement Study, almost half required decision making, of whom 70% lacked decision-making capacity.[18] A recent systematic review of surrogate decision making included 29 quantitative studies, wherein one third of surrogates reported a negative emotional burden as a result of having to make treatment decisions for a patient.[19] These figures suggest that advance care planning not only benefits patients but also protects caregivers.

Promise of Video Educational Media

Our work with video educational tools has demonstrated palatability and effectiveness in enhancing patient understanding and preferences in several disease states, including dementia[20] and cancer.[21] After 6 weeks in the multicentered randomized study of 200 patients with dementia, 29% of patients in the verbal information group changed their preferences for health care (life-sustaining *v* basic *v* comfort care), compared with only 6% in the video education group ($P < .001$).[20] In the randomized controlled study of care preferences of 50 patients with malignant glioma, patients who viewed an educational video about these three care options (life-sustaining *v* basic *v* comfort care) in addition to listening a narrative chose significantly fewer life-sustaining therapies and had less uncertainty than the verbal-only group ($P < .002$).[21] Ongoing studies with video decision-aid media span several settings, including those with oncology outpatients and those with inpatients on medical floors or in intensive care units or skilled nursing facilities.

Respecting Patient Individuality Along a Disease Trajectory

Admittedly, in view of religious, cultural, or temperamental considerations, willingness to engage in such discussion is not a quality shared by all patients or families, and future research must investigate strategies for health care professionals to approach encounters across these diverse and sometimes challenging settings. Although taking stock during structured introductions is likely the most effective first step, unanswered questions remain regarding how best to readdress patient wishes as individual disease trajectories unfold. Too often, as medical providers, we default to providing therapies and interventions to patients nearing the end of life because of the difficulties in effectively discussing potential benefits, limitations, harms, and alternatives. Although establishing health proxies and assessing patient perspectives from the time of diagnosis are necessary starting points, continuous support of patient autonomy through thoughtful discussion when changes in disease courses occur are critical times for revisiting advance care planning to ensure care delivery consistent with stated preferences.

Out With the Old, In With the New

Physician deficits in such proactive communication initiatives may partially account for the negative results seen in the landmark multicentered Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), in which 4,804 patients hospitalized with life-threatening illnesses (including lung and metastatic colon cancers) were randomly assigned to usual care versus multiple contacts with nursing staff specially trained in addressing (and highlighting to physicians) patient symptom burdens, treatment preferences, and disease knowledge. There were no differences in pain scores, timing, or incidence of do-not-resuscitate orders; intensive care or hospital resource utilization; or agreement between patients and physicians on preferences for such life-sustaining therapies.[22] As the authors note, these end points may have been more positively influenced had physicians been actively involved in carrying out the interventions and doing so at early time points in patient illness.

As noted in a 2008 systematic review of end-of-life palliative care, "older research has focused on legal, administrative and utilization outcomes of advance care planning. However, more recent research emphasizes broader interventions including trained facilitators, involving key decision makers, and addressing care across settings."[23(p155)] As such, the palliative care intervention to which patients newly diagnosed with metastatic lung cancer were randomly allocated in the 2010 study by Temel et al[24] was early, took place in the ambulatory setting, and included education about illness, coping strategies, and decision making. Patients randomly assigned to the early palliative care arm experienced significantly greater quality and length of life. Although 32% of the entire cohort at baseline believed that their illness was curable, significantly more patients gained or retained an accurate perception of their prognosis in the palliative care arm (82.5%) compared with those in the control group (59.6%).[25] The intervention arm also received significantly less chemotherapy near the end of life, demonstrating the effects of advance care planning on treatment of patients with cancer. Care satisfaction effects can also be seen in settings of long-standing illness: In a prospective cohort study of 686 chronically ill general medical patients whose outpatient physicians were computer-prompted to broach advance directives, such discussions were associated with significantly increased (and long-lasting) patient satisfaction.[26]

A significant barrier to dealing with evolving disease states is the apparent dichotomy between directing treatments against a given illness and palliating the associated symptoms and psychosocial effects. On a philosophic level, the above initiatives demonstrate that we continue to make strides in realizing that advance care planning and palliative care can effectively act in synergy (to enhance both quality of life and even survival[24]) with treatments for diseases and do not represent opposing efforts that deny hope or signal surrender. In an era of personalized medicine, we must continue to tailor treatments on both molecular and psychosocial levels. Critical to this is a reexamination of the reimbursement practices for care aimed at the latter. Fortunately, the Centers for Medicare and Medicaid Services have been required to execute a concurrent care-demonstration project as part of PPACA[27] specifically to evaluate expanded hospice-eligibility criteria. Such initiatives can potentially galvanize the transition from physician-centered all-or-nothing decision making to a more rational and shared process factoring in unique aspects of each patient's illness and individual perspective on it. In some countries, the approach to illnesses such as advanced cancer often entails the concurrent initiation of disease-directed therapy and palliative/supportive care from the time of diagnosis, a paradigm that likely serves to more effectively prevent and treat symptoms as well as initiate communication regarding goals of care and future planning, which more naturally evolves over time.

Reexamining the Case Example

Our patient with newly diagnosed advanced pancreatic cancer concluded the encounter by noting that "we feel so much better having discussed all this," accompanied by nods from her husband and son. That day, we had neither prescribed medications nor performed procedures, yet there was a benefit to the communication alone in outlining the goals and expectations of care as well as the intent to continue with regular future discourse. In this context, it is laudable that the American Society of Clinical Oncology recently published a detailed and patient-centered education booklet[28] on advance care planning, encouraging oncologists to discuss the relevant issues and resources with those facing diagnoses of advanced malignancy.

Conclusion and Take-Home Message for the Practicing Oncologist

Advance care planning is about much more than the generation of advance directives. At the cornerstone of the process rests communication initiatives at the individual and policy levels. Additionally, we must place more emphasis on interpersonal attributes when evaluating applicants for entry into the field as medical students. Medical curriculae on patient communication need to be enhanced, across several levels, from basic skills taught in medical school to more specialized and intensive training for physicians in residencies and fellowships responsible for the care for patients with chronic and advanced illnesses. Courses such as Oncotalk illustrate that communication skills can effectively be taught,[29] and such interventions, when practiced and utilized well, can serve to make a difference in the care of patients alongside medicines and procedures.[30] As society advances on a policy level, and as research continues to guide the application of evolving care practices, physicians should continue to exercise one of their most powerful therapies: Through careful, continuous, and patient-centered communication, we can strike a balance of maintained hope and empathetic realism in tailoring care aimed at achieving the individual goals of our patients.

Accepted for publication on September 8, 2011.

Acknowledgment

Supported by Grant No. K08HS018780 from the Agency for Healthcare Research and Quality (A.E.V.). The content is solely the responsibility of the authors and does not necessarily represent the official views of the Agency for Healthcare Research and Quality.

Authors' Disclosures of Potential Conflicts of Interest

The authors indicated no potential conflicts of interest.

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DOI: 10.1200/JOP.2011.000355

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Taking Care: Community, Family, and Dying in Place

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Introduction

Some time ago, early in my practice in Austin, a patient, well aware that she was dying of her cancer, talked to me about how she wanted to die. She would be looking out at the woods behind her house with her family near, still sensing the pulse of life around her. Her wishes were realized and we can say she "died in place." As important as it is to fulfill our wishes about the circumstances of our death, this often does not happen. Circumstances conspire to impede our wishes and we die in the hospital or in pain, or more often than necessary, both. Yet, as we shall see, it does not have to be this way.

That we have preferences about how we die is not in doubt. We have seen this in how we describe our deaths. On a day last summer (August 4, 2010) the following appeared on separate patients in the Statesman obituary column: ". . . were at her side when she died . . .," ". . . died peacefully . . . with his family by his side . . .," ". . . passed peacefully . . .," ". . . passed away at his home . . .," ". . . passed away with her family by her side . . .," and ". . . passed away peacefully at home."[1]; These sentiments are supported by a national survey of more than 2,500 Medicare-age patients that indicated 86% wanted to die at home; only 9% wanted to die in the hospital.[2,3] Yet we know that, for patients with cancer specifically, this is not how things play out. A recent report of the Dartmouth Atlas Project showed that 29% of Medicare-age patients dying of cancer die in the hospital. Twenty-four percent were admitted to the intensive care unit in the last month of life. Additional indicators of aggressive care were identified: chemotherapy in the last 2 weeks of life, low hospice admission rates, and late hospice admissions (3 days or less before death). Moreover, project data indicate that aggressive care in these cancer patients does not mean better care.[4] A recent article by Temel et al reinforced this point.[5] In this study of patients with lung cancer, one group received standard care and the other group received standard care plus consultation directed toward symptom control and quality of life. This latter group received less aggressive care with fewer hospitalizations and more hospice enrollments. Notably, in this group, symptoms were better controlled and family satisfaction was better. And these patients lived at least as long.

Austin is not immune to these concerns. In Austin, 23% of patients with cancer die in the hospital. The number of days in hospital in the last 30 days of life is 4.4, compared with a national mean of 5.1. Days enrolled on hospice are 10.6, compared with a national mean of 8.7. Chemotherapy in the last week of life was 7.8% of patients, compared with a national mean of 6%. Our practice, Texas Oncology, looked at its own experience during this same time frame.[6] Seventy-five percent of patients were enrolled in hospice at the time of death, with 57% dying at home and 28% dying at Hospice Austin at Christopher House (a free-standing inpatient hospice). More than 80% of these patients had pain well controlled. For patients not on hospice who died in the hospital, the last measurement indicated poorly controlled pain in 37.5%. A hospice enrollment of 3 days or less was associated with more severe pain levels.

A critical issue in this tension between wished for and actual place of death appears to be communication. A study of oncologists done in 2002[7] indicated that 37% of oncologists discussed do-not-resuscitate orders at the time of diagnosis, 41% only when treatment was not working, 10% just before hospice referral, and 12% a few days or hours before death. In contrast, 90% of patients want to talk about advance care planning at the time of diagnosis and want to discuss this while they are still well.[8] The consequence of this disconnect between oncologist action and patient desires is a misperception by the patients as to the likelihood of cure and predictable outcomes. Recent studies by Wright et al[9] and Temel et al[10] indicate that this situation can be improved by honest discussion about the goals of care.

The cancer community has recognized these shortcomings, and medical schools now more regularly offer courses in communication. There are also programs, such as Respecting Choices[11] and Oncotalk,[12] available to practicing professionals to help structure and add comfort to these discussions. Yet, the most critical aspect of improving com-