

Advance Care Planning: Negotiating Plan B

Internal Medicine Grand Rounds
UT Southwestern Medical Center at Dallas
July 8, 2011

Plans are nothing; planning is everything.
Dwight D. Eisenhower, reflecting on the allied invasion of Normandy

Death is less bitter punishment than death's delay.
Ovid (43 B.C.-A.D. 17/18)

M. Elizabeth Paulk, M.D., F.A.C.P.

This is to acknowledge that M. Elizabeth Paulk, M.D. has no financial interests or other relationships with commercial concerns related directly or indirectly to this program. Dr. Paulk will not be discussing off-label uses in her presentation.

Part One: Introduction

It is hard to open a newspaper or web browser today without hearing about the rising costs of healthcare. Medical costs in the year prior to death are often the highest in a person's life, but what are we getting in return? As the baby boomers age, bringing greater consumer pressure to issues associated with aging, there is increased scrutiny on the experience of chronic and terminal illnesses, and it is shining a light on a very big problem. Care in the last year of life is very expensive, but the quality outcomes do not differ significantly based on the amount of money spent.¹ An Institute of Medicine report noted that "people have come both to fear a technologically over-treated and protracted death and to dread the prospect of abandonment and untreated physical and emotional distress."^{2,3} We are providing expensive care of marginal utility that often does not meet the goals of the recipients. How did we get ourselves into this situation, and how do we get out?

As a culture, we have lost our familiarity with death

At the turn of the last century, average life expectancy was in the 40's, infant mortality was sky-high, and people died regularly and suddenly of accidents and infectious diseases⁴. Effective treatments for heart failure and cancer were virtually non-existent. Death was a constant companion, and was understood to be able to strike at any time. These days we have such incredible therapies for saving and prolonging lives that we and the general public have enjoyed the luxury of pretending that death is preventable, and that medical technology can overcome whatever roadblocks mortality throws in the way. Patients can undergo life-saving surgeries, survive traumas that previously would have been lethal, and survive infectious disease that would have been lethal in the 1950's. Newer chemotherapeutic options have made it possible to prolong the lives of patients with illnesses that would otherwise be rapidly fatal. As a medical culture, we are like a sixteen-year-old with a muscle car – we have a lot of power in our hands, but don't yet have the experience to keep it under control. As physicians, we are from time to time forced to face reality, both personally and professionally, but we have gotten out of practice in helping patients and families anticipate death as a possibility, and making the experience as painless as possible when it is inevitable. Consequently, many patients with chronic and terminal illnesses pass through a gauntlet of expensive and aggressive care to stave off death, enduring significant discomfort. Advance directives, specifically living wills, were proposed in the late 1960's to ensure that patients got the kind of care they wanted. 21 years after the enactment of federal legislation to maximize the use of advance directives, we are still not providing the kind of end-of-life care patients and families want.

Part 2: Patient goals at End-of-Life

When considering whether our current system meets the needs and goals of patients facing serious illness, it is useful to know specifically what those goals are. Dr. Karen Steinhauser⁵ interviewed patients, recently bereaved family members and providers about what each group felt were key elements of a good death. Table 1 shows the attributes that were agreed on by all parties. At the top of everyone's list is freedom from pain. Strikingly, there are only two other strictly medical goals – being mentally aware and having treatment choices followed. One of the challenges of providing good end-of-life (EOL) care is being able to attend to issues that are important to patients and families but that do not feel particularly salient to physicians. Table 2 shows which attributes were very important to patients and families but not to physicians. Much of what is important to patients are not things we would necessarily consider our province, falling more in the area of "life work" –examining the meaning of their

Table 1: Mean Rank Scores of 9 Preselected Attributes*

Attributes	Patients	Bereaved Family Members	Physicians	Other Care Providers
Freedom from pain	3.07 (1)	2.99 (1)	2.36 (1)	2.83 (1)
At peace with God	3.16 (2)	3.11 (2)	4.82 (3)	3.71 (3)
Presence of family	3.93 (3)	3.30 (3)	3.06 (2)	2.90 (2)
Mentally aware	4.58 (4)	5.41 (5)	6.12 (7)	5.91 (7)
Treatment choices followed	5.51 (5)	5.27 (4)	5.15 (5)	5.14 (5)
Finances in order	5.60 (6)	6.12 (7)	6.35 (8)	7.41 (9)
Feel life was meaningful	5.88 (7)	5.63 (6)	5.02 (4)	4.58 (4)
Resolve conflicts	6.23 (8)	6.33 (8)	5.31 (6)	5.38 (6)
Die at home	7.03 (9)	6.89 (9)	6.78 (9)	7.14 (8)

*From Steinhauser, et al. (2000) JAMA – How patients, bereaved family

lives, solidifying relationships, and trying to not to be a burden. Two particularly interesting findings also warrant comment. First is the importance for patients of feeling they are able to help to others. Second is the pivotal role of spirituality among terminally ill patients, particularly the importance of coming to peace with God and praying. “Coming to peace with God and pain control were nearly identical in importance for patients and bereaved family members.”⁵ Finally, all groups advocated strong relationships between patients and health care professionals that emphasized more than just the patient's disease⁵. Multiple other studies have confirmed the importance of such “non-medical” goals at EOL. Singer et al. ⁶ identified the five top priorities of terminally ill patients as: pain and symptom control, avoiding inappropriate prolongation of the dying process, achieving a sense of control, relieving burdens on family, and strengthening relationships with loved ones. Tolle et al⁷ found similar, but not identical, results among 475 bereaved caregivers, who identified as their top priorities honoring the wishes of their loved ones, being included in the decision process, practical assistance (including help at home, transportation, and personal care needs), honest information, access, to be listened to, privacy, and to be remembered and contacted after the patient's death.

Regardless of their role, respondents converged on the importance of preparation for the end of life. These findings echo the results of a recent study that showed that many patients wish to plan ahead for their own deaths and support the importance of prognostication in clinical practice. Respondents expressed a strong preference for having an opportunity to gain a sense of completion in their lives through life review, saying good-bye, and resolving unfinished business.⁵

Is what we are doing now meeting patient goals for End-of-Life Care?

Freedom from Pain

The first goal mentioned in Steinhauser's study is freedom from pain, and the available data suggest that we do not do very well in that regard. In the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), examining the end-of-life experiences of 9000 seriously ill patients at 5 major teaching hospitals it was found that overall

pain control was very poor. Specifically, up to 60% of patients were still in moderate to severe pain 8 to 12 days into hospitalization and over 50% of patients had serious pain the last 3 days of life. The pain was not just physical. Patients, families, and even the providers reported significant emotional suffering related to the hospitalization. There was a big financial burden on families, and 31% of those caring for a terminally ill family member lost most of their life savings. 38% of the dying patients in SUPPORT spent at least ten days in the ICU.⁸ Nelson^{9,10} and her group found that “post-discharge recollections of survivors indicate that ICU patients commonly experience distressing symptoms at levels of severity that are substantial and are underestimated by caregivers.” Success in management of other goals other than pain management is equally, if not more, elusive.

Getting better or feeling better

A stay in the ICU would be well worth it if it made people feel better, live longer, or helped them spend more quality time with family and friends. Unfortunately, that does not seem to be the case for the majority of seriously ill patients. Obviously, it can be challenging to determine whether an ICU stay is likely to be part of a terminal event, but there exist data about which patients are likely to benefit. In a study of the survival of cancer patients in the ICU's at five top cancer centers, the survival data for those who are sent to the ICU is not very promising¹¹. For example, of 75 patients who went to the ICU with DIC, 57 (76%) did not survive. The mortality of those requiring mechanical ventilation was nearly 70%, whereas almost 90% of cancer patients with poor neurologic function at ICU admission died before hospital discharge (see Table 3). Even for those patients who survive hospitalization, prognosis remains grim. In another study, approximately 75% of cancer patients who survived hospitalization died in less than three months.¹² The cost per year of life gained, incidentally, was \$82,843 for solid tumor patients and \$189,339 for hematologic malignancy patients in unadjusted 1991 dollars.¹² Interestingly, having a DNR order in place conferred a better prognosis than having hepatic failure. None of this is to say that patients with advanced illness should not go to the ICU if it is their wish, or if it is likely to meaningfully improve their health or life span. It is essential, however, that patients understand what can be done in the ICU and what cannot, and what the experience will be like. For many patients with advanced illness who go to the ICU, their last days will be spent there.

Even more worrisome are the statistics about the effectiveness of CPR in patients with advanced illness. Cardiopulmonary resuscitation is performed on approximately 1% of hospital admissions and in 30% of in-hospital deaths.^{13,14} For example, Bedell and colleagues¹⁵ reviewed the charts of 160 men and 134 women between the ages of 18 and 101 who underwent CPR at Beth Israel in Boston. Overall, 128 (44%) survived the arrest, and 41 (32% of survivors, 14% overall) survived to discharge. Those who were hospitalized for a cardiac etiology did better than patients with other illnesses, but among some groups the survival rates were abysmal. For

Table 2: From Steinhauser, et al. (2000) JAMA
How patients, bereaved family members, and physicians ranked different attributes of End-of-Life Care

Attributes	Participants Who Agreed That Attribute Is Very Important at End of Life, %	
	Patients	Physicians
Be mentally aware	92	65
Be at peace with God	89	65
Not be a burden to family	89	58
Be able to help others	88	44
Pray	85	55
Have funeral arrangements planned	82	58
Not be a burden to society	81	44
Feel one's life is complete	80	68

*P<.001 for all comparisons.

example, none of the patients with renal failure on dialysis or with metastatic cancer survived. Only 4% of the 137 patients who were homebound prior to admission survived. The bottom line is that when people who are dying die, there is very little we can do to reverse the process. Unfortunately, physicians, patients, and the general public grossly overestimate the likelihood of survival after cardiopulmonary resuscitation. Most patients cite television shows as their primary source of information about resuscitation.^{16,17}

Variable		Died		Lived		P value
		#	%	#	%	
GI bleed	Yes	66	43.7	85	56.3	.619
	No	555	41.6	779	58.4	
DIC	Yes	57	76	18	24	<.001
	No	564	40.1	844	59.9	
Hepatic failure	yes	54	67.5	26	32.5	<.001
	No	567	40.4	838	59.6	
Ventilated, except post-op	Yes	260	69.0	117	31.0	<.001
	No	361	32.6	747	67.4	
DNR	Yes	34	59.6	23	40.4	.005
	No	587	41.1	841	58.9	
Limits on care	Yes	39	60.9	25	39.1	.002
	No	582	41.0	839	59.0	
Living Will	Yes	99	49.5	101	50.5	.008
	No	402	39.4	618	60.6	
Vasopressors	Yes	172	58.5	122	41.5	<.001
	No	449	37.7	742	62.3	
GCS <=5	Yes	62	87.3	9	12.7	<.001
	No	559	39.5	855	60.5	

Table 3: How do patients with advanced cancer fare in the ICU?

Modified from: Groeger, J. S., S. Lemeshow, et al. (1998). "Multicenter outcome study of cancer patients admitted to the intensive care unit: a probability of mortality model." *J Clin Oncol* 16(2): 761-770.

More is not necessarily better

We have been operating on the principle that more care is better care, when sometimes it is just more expensive. Finding the balance point between the two can be very tricky work. Intensive care is an expensive and limited resource, consuming up to 20% of the entire hospital budget and 1% of the nation's gross domestic product.¹⁸ While we do not seem to be meeting some of the goals expressed by terminally ill patients, are we at least getting good value for our money? The variation across the country in intensity of services in the last six months of life provides us with the opportunity to see if outcomes are correlated with spending; whether more expensive care results in better outcomes. When researchers working on the Dartmouth Atlas project compared academic hospitals from the highest and lowest spending quintiles, there was no difference in mortality outcomes or patient satisfaction among patients with hip fracture, MI and colon cancer despite a 60% difference in expenditure. In fact, the authors observe that "greater frequency of use was associated with worse outcomes: quality and access to care were slightly worse in higher spending regions, and mortality was between 2% and 5% higher, suggesting that overuse of supply sensitive services was leading to harm, possibly because greater use of hospital and specialist care exposes populations to greater risks of medical errors."¹

So, we are spending a lot of money to provide interventions that are not especially effective at the end-of-life and do not seem to meet the goals of patients and families. That is not to say that there are not times it is worth the risk. The kinds of care we can provide in the Intensive Care Unit are nothing short of miraculous, and should be available to all patients for whom they can be of benefit. The question is how we can help patients avoid unwanted suffering, and spare the expense of treatments that will not be of benefit.

Part 3: For every problem, there is an obvious solution

As early as the late 1960's, it was becoming clear that it was not in the best interest of every patient to receive aggressive medical interventions as death drew near, but often the patients in question were sedated or too ill to speak for themselves. There was no recognized way to respect the autonomy of this vulnerable population. When the wishes of the patient are unknown, aggressive interventions can continue far beyond their potential usefulness because neither the physician nor the family member wants to be responsible for "giving up." Put forward as the solution to preserving patient autonomy in this context were advance directives – written, legal documents that ideally would describe what kind of treatments a patient would wish, and/or who would act as their proxy decision-maker for healthcare issues, in the event of incapacitation. It is intuitively logical that giving patients a choice about what kind of care they want to receive, and then using that information to guide decision making should solve the problem of knowing how patients want to be treated, and limiting exposure to undesired interventions.

History of Advance Directives

Cardiopulmonary Resuscitation, or CPR, was first introduced in 1960 for the purpose of intraoperative rescue, but its use was soon expanded widely. Soon there was a population of seriously ill patients clinging to life despite, in many cases, terminal illness. There was little knowledge about the benefits of CPR for patients who were dying, but nonetheless it quickly became the default treatment¹⁴ (In fact, CPR remains the only procedure for which you must give consent not to receive it). Many providers were aware from the start that CPR, and subsequently other aggressive treatments, were being provided to patients who "cannot, or do not wish to endure" such burdens¹⁹ but there were no protections under the law for physicians who wanted to limit treatment in what they felt was the patient's best interest. In the eyes of the court, a patient's best interest was always to remain alive. At the same time, many of the seriously ill patients were too incapacitated to refuse intervention on their own behalf. Patients and families were unsatisfied with the lack of autonomy they felt in the face of this new technology. It became clear there was a need to ask new legal and ethical questions about how to optimize respect for patient autonomy and informed consent at times when the patient no longer had decision-making capacity. The concept of advance directives was first put forward in 1967 by Luis Kutner, a human-rights lawyer, who proposed that individuals should create documents outlining how they wished to be cared for in the event that decision making capacity was lost.²⁰

Advance directives, such as the living will, medical power of attorney, and later the out-of-hospital do not resuscitate order were designed by lawyers and adopted by state legislatures as ways to ensure informed consent and preserve autonomy.²⁰ The Directive to Physicians (or "Living Will") was first adopted statewide by California in 1976, and was a standardized instrument designed to express patient wishes regarding life-sustaining treatment in the event of a terminal condition or permanent unconsciousness, while protecting the physician from prosecution if the wishes were followed in good faith. In Texas, the Natural Death Act in 1977 authorized

physicians to carry out advance directives.²¹ As their use increased, it became clear that living wills were too narrow in focus to address all the issues that might arise. A document that fully anticipated all possible consequences would be unmanageably long. The proposed solution was what we now know as the Durable Power of Attorney for Health Care, allowing a proxy decision-maker to represent the patient's wishes. The California legislature led the way by authorizing the medical power of attorney in 1983, Texas followed in 1989, and by the end of 1997 every state had some version.

All of these legislative efforts culminated in the Patient Self-Determination Act (PSDA), passed as part of the Federal Omnibus Reconciliation Act of 1990. The goal of the legislation was to make sure that all patients had an opportunity to discuss advance directives, and have their wishes documented and acted upon.²⁰ It requires all Medicare and Medicaid provider organizations (specifically, hospitals, skilled nursing facilities, home health agencies, hospices, and prepaid health care organizations) to do five things:

1. Provide written information to patients concerning their right under state law to make decisions about their medical care and the right to formulate advance directives.
2. Maintain written policies and procedures regarding advance directives and make them available to patients upon request.
3. Document whether or not the patient has executed an advance directive.
4. Comply with the requirements of state law respecting advance directives.
5. Educate staff and community on advance directives.²⁰

The legislation has continued to evolve. In 1993, Congress passed the Uniform Health-Care Decisions Act which establishes "very simple rules for recognizing almost any kind of written or oral statement as an advance directive."²⁰ It provides "an optional sample form with options to give instructions about one's care, appoint an agent, make an organ or tissue donation, and name a primary physician. The act also recognizes default surrogates in the absence of an advance directive."²⁰ In the absence of any directives, family or other surrogate can make the decisions.

The out of hospital DNR (OOH-DNR) is a physician order to withhold CPR from terminally ill outpatients, including hospice and nursing home residents. It was created in response to reports that terminally ill patients living at home or in hospice were getting resuscitated because emergency medical personnel did not have a physician order to withhold CPR. Texas legalized the Out-of-Hospital-Do-Not-Resuscitate Order in 1995. In 1999, all three directives were combined as part of the Texas Advance Directives Act in 1999.²¹

In 2008, Congress added "end-of-life planning" to the one-time only, initial preventive physical examination (sometimes called the "welcome to Medicare exam") available to newly enrolled Medicare beneficiaries. Derided as a "Death Panel" in the popular press, it was summarily eliminated from the final version of the bill to reform health care financing that passed in 2009.

The net effect of all this legislation is to create what Sulmasy²² refers to as the Tripartite System. In the event that a patient becomes incapacitated, providers are expected legally and ethically to abide by any written wishes, specifically a living will, the patient might have executed. Only in the event that there are no written wishes does the decision go to a designated proxy, or medical power of attorney. Finally, if there is no designated proxy, the decision-making authority goes to a family member as outlined by rules of the state. Legally and ethically, a written directive to physician trumps the care preferences of the family members.

Part 4: Shortcomings of Advance Directives and the Patient Self-Determination Act

Intuitively it is in everyone's best interest to participate in an organized campaign of advance directive completion as laid out by the Patient Self-Determination Act (PSDA). However, what seemed to be a simple solution from a legal perspective turned out to be far more complicated in medical practice. 21 years after passage of the PSDA, which cost the American Health Care system approximately \$101,569,922 to enact²³ many experts now question whether living wills are an effective intervention at all. ²⁴⁻³⁰ Fagerlin and Schneider observe, "In an attempt to extend patients' exercise of autonomy beyond their span of competence, resources have been lavished to make living wills routine and even universal. This policy has not produced results that recompense its costs and it should therefore be renounced...Such persistence in error," they observe, "is but the triumph of dogma over inquiry and hope over experience." (Fagerlin and Schneider 2004) Others have compared the PSDA to Miranda warnings explaining the rights of individuals in police custody. Both meet the letter of the law, but nonetheless remain incomprehensible to most they are designed to protect and do not seem to be meeting the goals for which they are intended.³¹

For living wills to be effective, people must actually create them. They must decide how they would want to be taken care of in the event of an as yet unanticipated adverse situation requiring complex medical judgment, and then "accurately and lucidly" state that preference in clear but legally acceptable language. The directives must then be available to all concerned parties at the time when they are needed, the surrogates who are left to interpret the document must be available as well as able to both understand and enact the patient's wishes. As it turns out, there are problems with almost every step in this sequence.³¹ Pope asserts the PSDA has "promoted the execution of uninformed and under-informed advance directives and has undermined, not protected, self-determination."³¹

Problems with Living Wills ("Directives to Physician")

Completion rates are low:

Living wills are seldom executed by anyone other than the terminally ill, and even then in sparing numbers.^{32,33} The number of living wills among patients with unanticipated critical illness is especially limited, with only 5–11% of patients having an advance directive.³⁴⁻³⁸ Among patients with relapsed hematologic malignancies, still only 32% had executed living will. ³⁹ The rates are about the same for hemodialysis patients³³ Fewer than 50% of patients of severely or terminally ill inpatients in SUPPORT had an advance directive on the chart.^{24,25,40,41} Other studies have reported that advance directives are more commonly completed in older patients and in patients who are diagnosed with serious illnesses^{23,42,43} Approximately 70% of inpatients end up with a do-not-resuscitate order at the time of death⁴⁴ The authors of that study observed, however, that many of the DNR orders are written only a few days before death, "thus serving as a surrogate marker for impending death rather than the result of a planned decision."⁴⁴

Why are completion rates so low?

A number of theories for the low completion rates of living wills have been put forward, including poor physician communication and fear that having a living will keep them from being considered for "highly technical therapeutic interventions."^{39,45} The latter turns out to be an unjustified concern, at least based on the literature. When Kish Wallace et al. compared 135 of the 27% of

ICU patients at M.D. Anderson who had advance directives with clinically similar counterparts who didn't have directives, there was no difference in the frequency with which patients received mechanical ventilation, inotropic support, CPR, or hemodialysis. They concluded that "patients with advance directives received life-supportive technology comparable with that of patients without advance directives."³⁹

There is also evidence that although many patients are willing to talk about planning for serious illness, for many it is simply uncomfortable. Elderly patients are among the most studied in this regard, and there is "considerable evidence that the elderly's action of delaying execution of advance directives and deferring to others is a deliberate, if not an explicit, refusal to participate in the advance directives process."⁴⁶

Physician communication and attitudes are also barriers to advance directive completion. There are a number of reasons, both practical and psychological, why physicians are not, as a group, as effective as might be hoped at discussing advance directives. Aside from issues of time, physicians also report they feel inadequately trained to discuss advance directives.^{47,48} Many report that they are not clear on what the goals should be for the discussion.⁴⁹ Clear identification and understanding of the goals, the literature suggests, "is a prerequisite to successful communication."⁵⁰⁻⁵⁴

Physicians are also troubled by the timing of discussions about advance directives, partially because of limitations of prognostic ability, and partially out of fear of upsetting the patient "prematurely."^{55,56} As it turns out, concern about upsetting the patients is largely unjustified according to the literature. Most patients are willing to discuss directives, particularly with their primary care provider (PCP). Only 5 percent of patients in one study stated that they found discussions about advance care planning too difficult.⁵⁷ In a number of other studies, patients who engaged in discussions had "less fear and anxiety, felt they had more ability to influence and better direct their medical care, believed that their physicians had a better understanding of their wishes, and indicated a greater understanding and comfort level than they had before the discussion."⁵⁸⁻⁶¹ Perhaps the greatest benefit of discussing these issues before a crisis arrives is that patients then continue the discussion with their families. "Such discussions enabled patients and families to reconcile their differences about end-of-life care and could help the family and physician come to agreement if they should need to make decisions for the patient."^{58,62}

Conversely, it has been amply demonstrated that a "lack of communication with physicians and other health care providers causes confusion about medical treatments, conditions and prognoses, and the choices that patients and their families need to make." Even among experienced providers who know patients well, it seems to be a difficult conversation to have. When Tulsky et al recorded experienced providers talking with their patients over sixty-five or seriously ill about advance directives, the conversations were short and one sided. The median discussion "lasted 5.6 minutes (range, 0.9 – 15), with physicians consuming, on average, 3.9 minutes (range 0.6 – 10.9 minutes) of the time. Generally, the conversation ended without a conclusion or a specific plan."⁴⁷

There are probably reasons other than lack of training that limit physicians' ability to communicate effectively about these issues. A thorough discussion of what these issues might be is an entirely separate Grand Rounds, but a few points are worth addressing. First, at least in the United States, there are certain things we are taught from the cradle not to talk about, and for most of us death is one of those things. Outside of a religious context, discussion of death is

relatively taboo. One of the major functions of medical education is to help physicians learn to overcome social taboos in order to be of the most use to patients. We have to discuss many things during a patient encounter that would be strictly off limits at a cocktail party. Broaching the truth that a patient's life expectancy is limited violates a number of taboos: discussion of illness, discussion of death and dying, and finally, the rudeness of refusing to participate in the delusion that the patient is going to be healed. This last one is especially problematic. Many people go into medicine with precisely the goal of curing illness, of fighting against death. To openly admit that a patient might not get better, or even to address that each of us is mortal, is a violation of the unspoken contract that doctor and patient will share an optimism that the patient will be cured. For either to say otherwise can feel like a betrayal. It may also feel to provider like a personal failure.

If executed they may not be helpful:

There is quite a volume of literature outlining why directives to physicians, if they exist, are not helpful. Three of the reasons discussed here are that 1.) the documents may not represent an informed decision 2.) language is vague and non-specific and 3.) preferences of life-sustaining treatment may have changed.

Living wills may not represent an informed decision

In the SUPPORT study, it was found that among the seriously ill patients who had advance directives, only 12% had input from a physician in its development.²⁵ This generates a number of problems, not the least of which is that it can hardly be assumed to represent truly informed consent about the risks and benefits of treatment available in any given situation.

It is well-documented that patients and families grossly overestimate the effectiveness of CPR and other critical care technologies, and their knowledge is mostly based on television viewing⁶³. For example, Gehlbach et al⁶⁴ found that although 83% of the 100 patients and surrogates interviewed in an ICU setting expressed a preference for CPR, only 4 could actually explain what CPR was, and the respondents' "average prediction of survival following in-hospital cardiac arrest with CPR was 71.8%." The higher the prediction of survival, the greater the frequency of preference for full code status ($P = .012$).⁶⁴ The entire history of advance directives was driven by the goal of achieving informed consent for incapacitated patients, and instead we have created a system wherein they make uninformed decisions that are then translated into legally binding documents. It is the complete opposite of what was intended. Fagerlin points out that we actually give people more information when getting consent for a flu shot than we do when discussing the risks and benefits of CPR.

How the care options are phrased in a directive also has a big impact on patient preferences. For example, in one study, 201 elderly patients were asked their preferences about an intervention in three different ways, negatively, as what they had already selected in a directive, or in a positive light. When the option was presented negatively, only 12% selected it, but when it was presented in a positive way, 30% selected it. "Seventy-seven percent of the subjects changed their minds at least once when given the same case scenario but a different description of the intervention."⁶⁵ Another illustration of this point comes from the Steinhäuser study.⁵ African Americans had higher odds than white participants of wanting all available treatments, but at the same time disagreed with the importance of "being connected to machines"⁵

Another reason directives may be ill-informed is that patients and families do not expect us to offer futile care we ourselves think is not likely to be of benefit. In the Coping with Cancer study,

we asked over 600 patients with stage IV cancer, “Do you think your doctor would offer you treatment that you are told would not help you just because he thought you wanted it?” The results were unambiguous: 92 percent (593) patients said “no.” In the interest of preserving patient autonomy, however, we tend to review all possible interventions as options, even if we do not think they will be effective. Curtis et al.⁶⁶ interviewed patients with AIDS about whether or not it was appropriate for physicians not to offer treatments judged by the physician to be futile. 61% (35) considered it “definitely acceptable” not to offer an intervention likely to be futile, and 26% (15) deemed it “probably acceptable.” Fewer than 10% of patients (n=5) said it was “definitely not acceptable.” Those patients who accepted physician decisions about futility were also less likely to prefer the intervention in hypothetical situations (p=.003) Factors that did NOT impact preference were health-related quality of life, patient satisfaction with medical care, and patient/clinician communication about end-of-life care⁶⁶ Although the numbers in the Curtis study are small, the message is very important. Patients do not expect us to offer a treatment we know will not work.

The language of living wills is vague

The language in advance directives is usually based on a template designed to be legally ironclad and apply to a wide variety of situations, but as a consequence, “was usually too nonspecific and general to provide clear instruction”²⁴ in SUPPORT. We get a hint about what patients are trying to say from an informal experiment Fagerlin reports. They asked each of their own patients and clients to explain the contents of their living will. “The modal answer is, in its entirety: ‘It says I don’t want to be a vegetable.’”³³ Coppola et al (Coppola, Ditto et al. 2001) put patients and physicians in separate rooms, and asked each party what the patient’s preferences would be in a variety of clinical scenarios. In half the cases, the physicians had a written directive to guide them. After reviewing the directive, the physician estimates of patient preference got closer to patient wishes, though errors of under treatment persisted. Surrogate decision-makers made only marginal improvement in accuracy after reviewing a directive⁶² Ultimately, in SUPPORT, advance directives were helpful in making end-of-life decisions in less than half of the cases where a directive existed.⁶⁷

The vagueness of the language in the living will also makes it possible for providers to read into what they want to see, so that “even with the therapy-specific AD accompanied by designation of a proxy and prior patient-physician discussion, the proportion of physicians who were willing to withhold therapies was quite variable: CPR 100%, administration of artificial nutrition and hydration, 82%, administration of antibiotics 80%, simple tests 70%, and administration of pain medicine 13%.”⁶⁸

Do preferences for EOL care remain stable over time?

There also remains the question of whether patient wishes regarding advance directives remain stable over time, or if they might change as the illness progresses, either because patients find they can tolerate a situation they had feared (e.g., loss of continence)⁶⁹, or because find they cannot or do not want to tolerate a situation they’d thought would not be an issue (e.g., fatigue). Over time patients may therefore choose to pursue more or less aggressive treatment. For example, patients are more likely to change their preference and desire for increased treatment when hospitalized, in an accident, depressed, or experiencing loss of functional or social activity.⁷⁰ Depressed patients may have fluctuating desire for CPR depending on the severity of depression.⁷¹ Outside of those circumstances, patients who had an advance directive maintained stable treatment preferences 86 percent of the time over a 2-year period, while patients who did not have an advance directive changed their preferences 59 percent of the time.⁷⁰ A meta-

analysis of eleven studies regarding the stability of preferences found that the stability of preferences was 71% (the range was 57% to 89%)⁷² with the general consensus being that directives are stable in times of calm, but fluctuate in times of crisis.

If executed, they may not be available or accessible

There are numerous problems with getting directives where they need to be. In SUPPORT and other studies, between 65 and 76 percent of physicians whose patients had an advance directive were not aware that it existed,^{25 41} and having an advance directive did not increase documentation in the medical chart regarding patient preferences.^{73,74} Directives are often executed with attorneys rather than in a medical setting, which puts the onus on the patient, often in a health crisis, to find a document that might have been executed long ago and bring it to someone's attention. There are also barriers to documenting care preferences both within and across care systems. If discussions occur, they are often buried in individual progress notes rather than in a place accessible to all. Use of electronic medical records increases the chance that wishes can be conveyed within a system, but how directives are exchanged across settings is also of crucial importance.⁷⁵ Unfortunately, documents are often lost in the shuffle. In one study, of 182 patients who had completed a living will before being hospitalized, only 26% of the charts accurately recorded information about those directives and only 16% of the charts contained the form.⁷³ In another study, only 35% of the nursing home patients who were transferred to the hospital had their living will with them.⁷⁴

If executed and available, they may not be implemented

There were well-described problems in the SUPPORT study with implementation of advance directives, particularly with living wills.⁷⁶ For example, patient preferences to decline cardiopulmonary resuscitation (CPR) often were not translated into do-not-resuscitate (DNR) orders on the chart.^{25,76,77}

One of the major barriers to implementing advance directives appears to be that it is hard to know exactly when they should apply. Tillyard observes, "the likelihood of general nonsurvivability from a critical illness is not an objective or precise tool, and there exists no perfect measure of QOL".³⁴ Furthermore, the quality of life six months after an acute illness is often (though not always) unpredictable "from the clinical information at the time of the acute illness."³⁴ Consequently, families and physicians are afraid to implement directives until the patient is "totally incapacitated"²⁷ and "absolutely, hopelessly ill."²⁶ No one wants to "give up" too early.

They have little impact on outcomes

Data from the SUPPORT study indicates that written directives to physician had little impact on clinical outcomes such as timing of do-not-resuscitate (DNR) orders, cost, and the duration of intensive care unit (ICU) stay⁸. 60% of surrogates stated that the directive helped only a little or not at all for patients who had one and died. There were "insignificant trends towards improvement in the provision of resuscitation."^{25,34} Several other studies have found that patients received life-sustaining treatment at the same rate regardless of their desire to limit treatment^{29,39}.

Benefits of the Medical Power of Attorney ("Durable Power of Attorney for Health Care")

Medical power of attorney is a far less problematic document than the directive to physicians. For one thing, all it has to accomplish is the naming of the proxy decision-maker. There is far less

ambiguity. Furthermore, even if no formal document has been executed, the Uniform Health Care Decisions Act enables a patient in most states (in front of a witness) to simply inform a provider verbally of who should be appointed. The greatest benefit of the medical power of attorney is that it allows providers to come much closer to achieving patient goals. Patients want providers to follow the spirit, rather than the letter, of directives to physicians. In both the SUPPORT and HELP trials, of 1,041 patients with clear preferences regarding resuscitation, more than 70% preferred family/physician to make decision in the event of incapacitation.⁷⁸ Armed with a general sense of a patient's wishes, providers can work with surrogates to adapt the philosophy of those wishes to a specific clinical situation. There are a few challenges, however, inherent in work with surrogates.

Surrogates may not be physically or emotionally available

In SUPPORT, surrogates named in advance directives often were not present to make decisions or were too emotionally overwrought to offer guidance.²⁶ It was also observed in SUPPORT and other studies that relatives cannot be relied upon to introduce directives at the onset of a critical illness. Sometimes the directives were used to "initiate less invasive support early on, and sometimes the directives were not made known at all."⁷⁹ In SUPPORT, it turned out that the presence of advance directives actually increased conflict between family members and physicians.⁴⁵

Surrogates may not be accurate, or willing to enact patient's wishes

The level of agreement between the "surrogate's decision and the patient's preference in real and hypothetical seriously ill scenarios was only 68% in a meta-analysis of 16 studies analyzing this outcome."⁸⁰ Surrogates who were family members tended to make prediction errors of overtreatment, even if they had reviewed or discussed the advance directive with the patient or assisted in its development.^{60,81} Having the patient and surrogate discussing an advance decision does not improve the surrogate's accuracy.⁸²

The surrogate may also be aware of the patient's preferences, but reluctant to enact them. For example, in one study looking at this issue, 76% of the surrogates whose family members were known not to want invasive treatment agreed invasive treatment was inappropriate, but all surrogates initiated it⁸³. They may feel an urgent need to keep the loved one alive.⁸⁴

Being a surrogate is hard work

Tilden et al. studied the impact of having acted as a surrogate decision maker, and found that it was an extremely stressful job. She describes the narrative comments: "Most described the decision as the hardest thing they had ever had to do. They used such terms as "difficult," "painful," and "exhausting" as they reported the impact of decision-making. Different individuals made similar statements, for example, "It was the hardest thing I have ever done in my life," and "I wouldn't wish this [reaching the decision] on my worst enemy."⁸⁵

Are Advance Directives Doing Any Good?

There are some studies that have shown if living wills are discussed, available, useful, and implemented that they can be of some value.⁴⁹ They have been shown in some studies to help reduce cost, hospitalization, and family stress.^{85,86} For example, in Kish Wallace's study at M.D. Anderson, patients with directives had a "greater likelihood of having a DNR order within the first 72 hours (19% vs. 11%, $p = .046$), shorter ICU stays and lower ICU charges"³⁹ even though the

rate at which life-sustaining therapies were offered was the same regardless of whether a directive was present. Other studies have confirmed a reduction in expenditures.⁸⁷ In one study, the average cost of end-of-life care in a university hospital was reduced from \$95,000 to \$30,000⁸⁸ because of shorter ICU stays.

One clear benefit occurs when the surrogate is aware of the patient's preferences. Although surrogate's familiarity with a loved one's preferences may not result in care that is more consistent with that patient's preferences, it does reduce the burden of decision-making on surrogates.^{60,85,89-91} What is not clear is the extent to which the paper directive was important, as opposed to knowledge of the patients' wishes.

Ultimately, there is "very little evidence regarding the effect that [living wills] actually have on the treatment of acutely ill patients in the ICU."³⁴ There may be some decrement in cost as a consequence of earlier DNR orders and shorter ICU stays. Unfortunately, the directives "will not invariably produce treatment that is consistent with the patient's wishes, however, and therefore it cannot be assumed to always facilitate harmonious decision-making at the end of life or to maintain an incapacitated patient's autonomy."³⁴

The biggest short-coming with the current model for advance directives is that it does not help patients achieve their goals for good end-of-life care. Perhaps the single biggest factor in that failure is that, aside from all the other shortcomings above, we are asking the wrong question. The directive to physician asks about the kind of care a patient would want in the face of terminal illness after having lost decision-making capacity. There is ample data that patients, families, and physicians are terrible at diagnosing the onset of terminal illness for a variety of reasons.⁸ Furthermore, a patient who has already lost decision-making capacity is the one who is least likely to benefit from interventions designed to optimize quality of life and time with family. What would be far more useful is a discussion that moves the implementation of plan of care further upstream – how would a patient want to be taken care of, what would the most important goals be if we knew that time was limited, rather than when death is imminent.

Part 5: The Goal (in most cases) is the Process, not the Paper

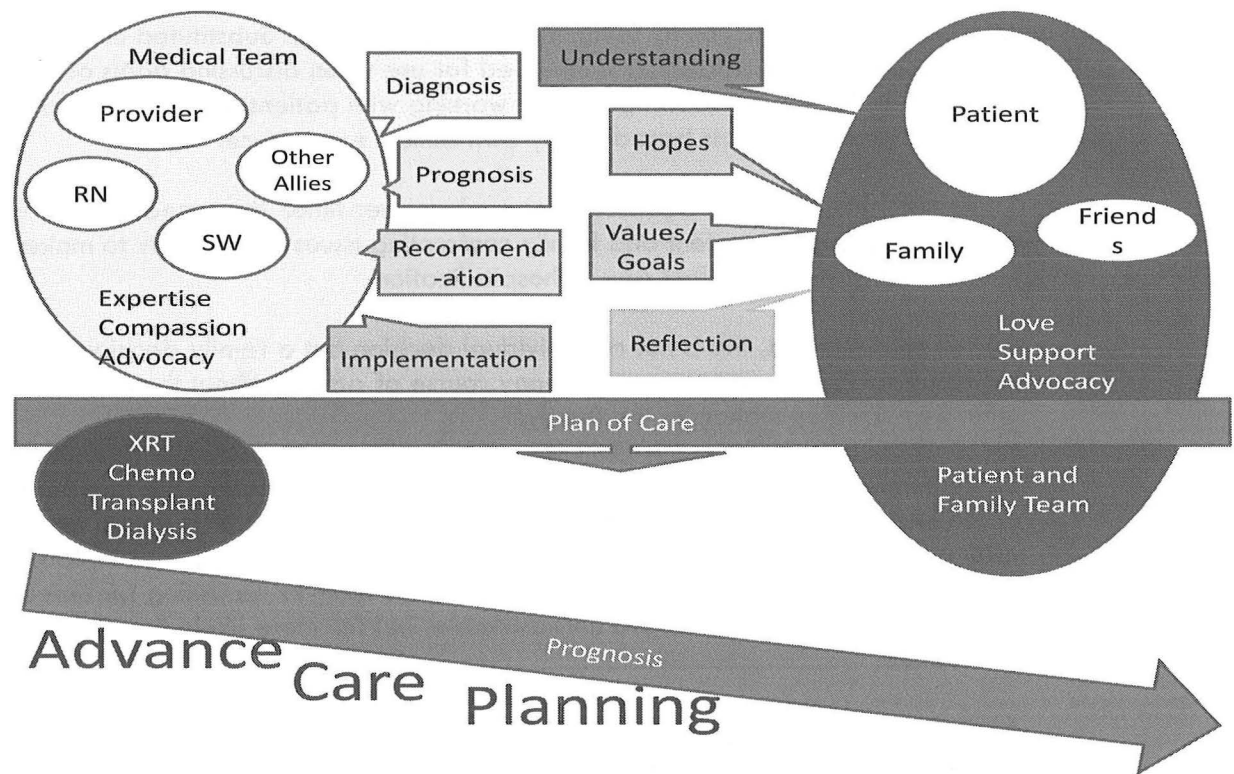
The most important part of advance planning is probably the conversation among patient, family, and medical provider, preferably before a crisis arises. In *Coping with Cancer*, Zhang et al.⁹² found that when 188 patients who had participated in EOL discussions (regardless of how aggressive the patients wished providers to be regarding interventions) were compared with a matched group who had not participated in discussion, there was a cost difference of \$1041 in medical expenses during the last week of life. Patients with higher costs were judged by bereaved family members to have had worse quality of death in their final week.

The patient-physician conversation is consistently lacking in the current process.⁸ No one is in a position to provide medical input to the same degree as the patient's primary provider related to the terminal illness, be that an Oncologist, Cardiologist, or General Internist.^{57,58,93-95} The goal of the conversation is not to document a laundry list of specific interventions, but to understand and document a philosophy of care that can evolve over time as prognosis and performance status change. The philosophy can be translated into specific preferences as health deteriorates.^{26,95} What ideally would also be documented is a designated surrogate.

There are a number of strategies for discussing patients' wishes for future care, and living wills are often central players in the strategy. Given the data presented above, I prefer a

conversation with patient and family using what Sulmasy calls the Substituted Interests Model. As outlined in his recent JAMA article²², it is intended for use when discussing goals of care with surrogates, but I believe it is a useful guide for working with patients as well. I offer these suggestions with several caveats based on my own clinical experience.

- 1.) Remember that this is a process that evolves over time. It is unreasonable, in my opinion, to expect a patient and family confronting issues of mortality to make a decision in one clinic visit or their first day of hospitalization.
- 2.) For most families, this is not an individual decision but a family decision.⁷⁸ Many individuals will not want to commit to any course of action without the participation of other key decision makers in the family.
- 3.) Remember that patients and families form their beliefs about CPR and the capabilities of modern medicine from television and other popular media.⁶³ It should never be assumed that a patient has an informed understanding of the options available. It is tempting to feel angry when patients and families seem to be asking for unreasonable care. It is possible that they are unreasonable, but far more likely that they are uninformed.
- 4.) Do not be discouraged if the next time you see the patient or family they deny all memory of the previous conversation. This is a common occurrence, and gentle reminders are part of the process. Only 50% of patients and surrogates remembered discussing goals of care in one study even after they were observed to have done so. ⁶⁴
- 5.) Remember that we live in the medical model – it is our metaphor for understanding life and death. The fact that we believe this to represent truth, rather than simply representing one of many valid paradigms for understanding the universe, tends to limit our ability to communicate with patients and families about what, in their mind, is often much more a religious or spiritual issue. Humility regarding possible outcomes is an essential component of the conversation.
- 6.) The intention of the provider is of tremendous importance. Patients and families can tell the difference between a provider who comes to them trying to talk them out of or into a particular course of therapy and one who comes to advocate for them and best understand their wishes. Patients and families are much more receptive to information that comes from an advocate, rather than an adversary.



The Substituted Interest Model of Decision Making (modified)

Step one: The first step, as with any patient interview, is to generate an empathic connection. This means acknowledging the stresses of the situation and the difficulty of the task for both the patient AND the family member. (e.g. - "It must be very difficult to see your loved one so sick" or "how are you holding up?") It includes introductions to all parties present, and clarification of their relationship to the patient and to each other. My observation is that the experience of terminal illness is almost harder on those who love him or her than on the patient. If the meeting or clinic visit has not specifically been called to discuss the plan of care, it is important to introduce the topic gently and with evidence of the correct intention. For example, "My job is to make sure that you get taken care of the way you want, especially if you cannot speak for yourself. In order to do that, I am going to need to ask you some difficult questions. Is this something you feel up to?" Some patients, either personal or cultural reasons will elect not to participate, in which case you can ask for their permission to speak with a family member.

Step two: Talk with family and, if possible, patient about what is important in his/her life: who the important people are, what brings meaning, what brings joy. Sulmasy calls these "authentic values", the elements that define the patient as a person. The question to the patient or surrogate can be as simple as, "In order to help you get the best kind of care, I need to understand more about who you are as a person - can you tell me a little bit about yourself (or about the patient)" ? Discussion might include a narrative of the illness and their understanding of its meaning, description of the family and the patient's role in it, work history, values (interpersonal, moral, religious), or incomplete life work (e.g. "I wish I could see my son one more time.") Some participants will be very explicit, and make statements such as, "I wouldn't want to be connected

to machines” or “He wouldn’t want to live like a vegetable.” They may also say something like “I’m a fighter, and I know I can beat this.” Directives might be part of this discussion if the family or patient has opinions about it (preferences regarding treatment, who decides and how). Sulmasy suggests, “Has anyone else in the family ever experienced a situation like this? How did you feel that went?”

Step three: Step three has two parts. The first part is to ask for the patient or family to explain what they understand about the current clinical situation. Some patients or surrogates will have very good insight into the situation, and having it reviewed repeatedly by multiple providers can feel very insulting. Only once you fully understand where the patient and/or family is coming from should you proceed to part two, which is an explanation of the clinical circumstances and prognosis. This needs to be done gently but honestly. It can be preceded with a statement such as, “I am going to be very honest with you about how things are going right now. I don’t want to hurt you, but it is important to make sure you have the information you need so we can come up with the best plan together.” It is also crucial in this step to be very humble about what outcomes are possible. Patients are very angry when we appear to be implying that we, rather than God, are in control of what will happen. Sometimes at this point a patient or family member will raise the issue of miracles. A useful response in that context would be, “Nothing would make me happier than to see you get well. We should keep hoping for that. At the same time, there is just no way to know for sure, and I think it is always a good idea to have a plan B. Let’s hope we won’t need it.”

Step four: This step is called the substituted interests stage when working with a surrogate, because we are asking the surrogate to help us understand what the real interests of the patient are, given the clinical circumstances and a mutual understanding of the patient’s values. “Knowing your loved one, what do you think would be most important for him or her right now?” It is very important that the surrogate understand his/her role as “helping clinicians to understand what outcomes of treatment align best with the patient’s goals” rather than being responsible for the final decision.⁹¹ When talking with patients, we do not have to use substituted interests, but can directly inquire about their real interests (comfort, increased life expectancy, time at home with family) and what they think will help them accomplish their goals. Patients want to discuss the risks and benefits of a wide range of interventions, including chemotherapy, feeding tubes, pacemakers, and surgery, rather than just CPR or mechanical ventilation.

Step five: In this stage, the clinician establishes a shared understanding of the options and offers a recommendation based on clinical experience and tailored to the patient’s real interests. “I understand that what you are telling me is that your mother was a very independent, happy person who loved talking and being around her family. It seems to me that what she would want most is to be awake and visit with everyone, even if it meant her life were a little shorter. Is that right?” “Here’s what we would recommend, based on what we know and what you’ve said about your loved one.” It is essential at this point to make a recommendation. We have had years of training to develop medical knowledge and clinical judgment and it is our obligation to give guidance in this extremely complex situation. Making recommendations about a plan of care consistent with a patient’s goals does not infringe on autonomy – quite the opposite. Without good information they cannot make a good decision. Sulmasy warns not to “abandon people to their autonomy.”

Specific details demonstrated to help patients and families make better decisions include information about invasiveness^{96,97}, and duration of therapy⁹⁸, chance of recovery⁵⁷, chance to

remain cognitively intact (proportions of adults rating dementia as being worse than death were similar among all groups, ranging from 18 to 31 percent),⁹⁶ prognosis, and risk of pain^{81,99}.

Step six: Together with the patient and/or surrogate, determine what would best promote the good of the patient as a unique person, in the context of his/her relationships, authentic values, known wishes, and real interests, given the clinical circumstances and options. “Knowing your loved one, does our recommendation seem right for him/her?” “Do you think another plan would be better, given his/her values, preferences, and relationships?”

Step seven: The last steps in a discussion about goals of care are to summarize in a way that clarifies all participants are on the same page. This is extremely important. Gehlbach et al reported that after 100 discussions about goals of care, there were 16 discrepancies between code status preferences expressed during the interview and code status orders in the medical record. (Gehlbach, Shinkunas et al. 2011). “So, are we in agreement that your mother would not want to get antibiotics for this infection?” At this point I should emphasize that execution of a directive to physician or durable power of attorney could occur at this point, but the two most important elements are 1.) a clear statement in your note explaining the patient or surrogate’s PHILOSOPHY and GOALS of care. Specific preferences can be included, but the goal is to craft a statement that can evolve with the clinical situation, and 2.) If talking with the patient, make sure you have a name and contact information for the surrogate regardless of whether you do a medical power of attorney.

Are there patients for whom a directive to physician is a strong option?

There is a group of patients for whom a directive to physician is probably a useful option. Fagerlin suggests directive to physicians would be useful for “patients whose medical situation is plain, whose crisis is imminent, whose preferences are specific, strong, and delineable, and who have special reasons to prescribe their care.” The groups that spring most readily to mind are patients receiving hospice care and patients with chronic, serious illness. The POLST paradigm has been very effective in Oregon, where it was first introduced in 1991.¹⁰⁰ Patients and families who have participated in a goals of care discussion and who are ready to translate their wishes into a physicians order can ask for a Physician Order for Life-Sustaining Treatment (or some variation on that acronym) that is valid across care settings. The orders specify “choices for cardiopulmonary resuscitation; medical interventions (directed at comfort, at full treatment, or at limited treatment); when or if the patient wishes to be transferred to a hospital or to an intensive care unit; and when or if the patient wishes to receive antibiotics, artificial nutrition, or hydration.” POLST is legally valid for care across all settings, including the home, nursing home, and acute care hospitals.^{100,101} In the pilot study for POLST, nursing home residents (n = 180), who had a POLST recording DNR designation and who indicated a desire for transfer only if comfort measures failed, were followed for 1 year. Only 38 subjects died over the course of the year, but none of them received CPR or went to the ICU. Two patients (5%) died in an acute care hospital. In only 15% of hospitalizations (n = 4), the transfer was to extend life, overriding POLST orders.⁷⁵ The POLST form appears to overcome the problems of vague language, availability, and utility across care settings. Although only ideal for a small subset of patients with life-limiting illness, it does seem a promising intervention for those with clearly defined goals who are likely to transition across settings. The National Quality Forum endorsed the POLST as part of a health care system’s quality standards in end-of-life care.

Part 6: Possible Solutions

Health System Leadership

One strategy with demonstrated effectiveness is leadership by a health system within a given community. The best-described example is the work of Gunderson Lutheran Hospital in La Crosse, Wisconsin. In this town of 52,000, more than 90 percent of residents have advance directives, but more importantly have participated in a discussion about goals of care. A community-wide care planning system was started in La Crosse in 1991. Implementation required changes on many levels, including institutional policies to make sure directives were available in the chart, staff education, clearly defined roles and expectations of physicians, training for advanced care planning facilitators, public and patient engagement, the execution of clinically relevant directives and incorporation of patient wishes into clinical care, and written protocols for emergency personnel enabling them to follow physician orders that reflect patient preferences. Quality improvement measures were then undertaken to measure outcomes.¹⁰² Patients and the public in La Crosse are offered participation in “Respecting Choices,”¹⁰³ a facilitated discussion about goals of care.

A study of the program’s effectiveness demonstrated that 85% of all patients in an eleven-month period had some type of written directive at the time of death, 96% of which were available in the chart where the person died. The most promising finding is that care in the last weeks of life was consistent with written instructions 98% of the time that directives were available.¹⁰² Patients were less likely to die in the hospital or have CPR, and used about \$2000 less in physician and hospital services in the last six months of life.”¹⁰⁴ “Gundersen patients spend 13.5 days on average in the hospital in their final two years of life, at an average cost of \$18,000. That is in contrast with big-city hospitals such as the University of California at Los Angeles medical centers (31 days and \$59,000), the University of Miami Hospital (39 days, \$64,000) and New York University’s Langone Medical Center (54 days, \$66,000).”¹⁰⁵

Recommendations for our system

As our population ages and the crisis in healthcare funding worsens, interest in advance care planning will grow as well. Care planning has the very attractive quality of improving patient care and patient/family satisfaction while (hopefully) reducing cost. The University of Texas Southwestern Medical Center at Dallas is well-positioned to become a leader in our community at helping patients preserve autonomy and attain goals for care at the end-of-life. Advance planning is an integral element of care for critically ill patients for whom outcomes are uncertain, particularly those with advanced cancer and patients eligible for heart¹⁰⁶⁻¹⁰⁸, lung¹⁰⁹, and liver transplants.¹¹⁰

What would it take to bring a system like the one at Gundersen Lutheran to UT Southwestern? We have a good head start with the electronic medical record. It could be modified to ensure the availability of directives within the system with relatively little effort. As in La Crosse, there would need to be up-front expenditure to train staff, particularly advance care planning facilitators, about how to have conversations about goals of care sensitively and effectively to come up with an individualized plan that is “specific not only to the patient’s values and goals, but also to his or her relationships, culture, and medical condition.”¹⁰² Physicians could be incentivized to participate financially, and by documentation of a “goals of care” discussion once annually in the medical record used as a quality indicator. Larger scale education of our patients could be achieved using shared medical appointments for teaching and directive completion for patients who desire it. A certain amount of culture change would be required as well. Legislation

approving a POLST-like form is likely to come up in the next session, but we could start using a similar document among our medical frail patients in the interim, without requiring that it be legally binding except as an indicator of patients' previously expressed wishes.

Conclusions

Written directives to physician may shorten ICU stays and therefore decrease costs, but they do almost nothing to help patients meet their goals for end-of-life care. Our efforts to help patients and families plan effectively for the future should be directed toward two goals in particular: educating patients about their illness and how available options can be of benefit, and having patients designate a surrogate who understands who they are as a person. The second goal is not especially onerous – it takes 10 seconds of a clinic visit. The far greater challenge is to communicate effectively with patients and families both before and during a crisis to help them understand how available treatments might or might not help achieve long-range goals. This is a process that takes some time, and at present is not well-reimbursed. It can also be an uncomfortable process to introduce. When we fail to help patients anticipate the kinds of obstacles they might be facing, however, we rob them of their autonomy, and leave them at significant risk of harm. Currently both New York and California have addressed the problem legislatively, requiring physicians to discuss with any patient who has a life expectancy of less than one year options for palliative care and hospice.

Legislating the art of medicine

While I agree in principle with the intentions behind the legislation, these laws are one more attempt to legislate something that should be outside the legislative realm. Participation in discussions about goals of care is really about the art of medicine. A good conversation requires knowledge of the science, communication skills to elicit preferences and convey prognosis, compassion for the experience of illness, and the courage to confront the specter of mortality. Sir William Osler wrote, "The good physician treats the disease; the great physician treats the patient who has the disease." When we help patients and families delineate goals of care by educating them fully about their illness and their options, and then tailor a plan of care that meets their goals as individuals, I believe we are living up to the ideal he describes. As Internists, we are optimally poised to assume that role.

When we live near suffering, near it but not in it, we are not the same. Of course, we hurt for those we try to help. But we also hurt because we see them, up close, so much like us. In here, they say. I'm still here. The same as I always was. We are partners with our suffering patients in a secret. They are not different. They are the same. The same as way back when, when they were healthy. When they were like everybody else. When they were like us. And when we go home, we still see them. We look at ourselves, our spouses, our sweet beautiful healthy children, and we realize that it could all be gone. Our normality, our life is not sacred. We are not immune.¹¹¹

References

1. Wennberg JE, Fisher ES, Stukel TA, Skinner JS, Sharp SM, Bronner KK. Use of hospitals, physician visits, and hospice care during last six months of life among cohorts loyal to highly respected hospitals in the United States. *BMJ* 2004;328:607.
2. Field MJ, Cassel CK. Approaching death: improving care at the end of life. *Health Prog* 2011;92:25.
3. Zeytinoglu M. Talking it out: helping our patients live better while dying. *Ann Intern Med* 2011;154:830-2.
4. Emanuel LL, Ferris FD, von Gunten CF. EPEC. Education for Physicians on End-of-Life Care. *Am J Hosp Palliat Care* 2002;19:17; author reply -8.
5. Steinhäuser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 2000;284:2476-82.
6. Singer PA, Martin DK, Kelner M. Quality end-of-life care: patients' perspectives. *JAMA* 1999;281:163-8.
7. Tolle SW, Rosenfeld AG, Tilden VP, Park Y. Oregon's low in-hospital death rates: what determines where people die and satisfaction with decisions on place of death? *Ann Intern Med* 1999;130:681-5.
8. A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). The SUPPORT Principal Investigators. *JAMA* 1995;274:1591-8.
9. Nelson JE, Mulkerin CM, Adams LL, Pronovost PJ. Improving comfort and communication in the ICU: a practical new tool for palliative care performance measurement and feedback. *Qual Saf Health Care* 2006;15:264-71.
10. Nelson JE, Meier DE, Oei EJ, et al. Self-reported symptom experience of critically ill cancer patients receiving intensive care. *Crit Care Med* 2001;29:277-82.
11. Groeger JS, Lemeshow S, Price K, et al. Multicenter outcome study of cancer patients admitted to the intensive care unit: a probability of mortality model. *J Clin Oncol* 1998;16:761-70.
12. Schapira DV, Studnicki J, Bradham DD, Wolff P, Jarrett A. Intensive care, survival, and expense of treating critically ill cancer patients. *JAMA* 1993;269:783-6.
13. DeBard ML. Cardiopulmonary resuscitation: analysis of six years' experience and review of the literature. *Ann Emerg Med* 1981;10:408-16.
14. Loertscher L, Reed DA, Bannon MP, Mueller PS. Cardiopulmonary resuscitation and do-not-resuscitate orders: a guide for clinicians. *Am J Med* 2010;123:4-9.
15. Bedell SE, Delbanco TL. Choices about cardiopulmonary resuscitation in the hospital. When do physicians talk with patients? *N Engl J Med* 1984;310:1089-93.
16. Adams DH, Snedden DP. How misconceptions among elderly patients regarding survival outcomes of inpatient cardiopulmonary resuscitation affect do-not-resuscitate orders. *J Am Osteopath Assoc* 2006;106:402-4.
17. Jones GK, Brewer KL, Garrison HG. Public expectations of survival following cardiopulmonary resuscitation. *Acad Emerg Med* 2000;7:48-53.
18. Polderman KH, Metnitz PG. Using risk adjustment systems in the ICU: avoid scoring an "own goal". *Intensive Care Med* 2005;31:1471-3.

19. Rubenfeld GD, Curtis JR. Improving care for patients dying in the intensive care unit. *Clin Chest Med* 2003;24:763-73.
20. SABATINO C. The Evolution of Health Care Advance Planning Law and Policy. *The Milbank Quarterly* 2010;88:211-39.
21. Watson RJ. Advance Directives in Texas: Advance Directives Act of 1999. Denton: Denton; 2000.
22. Sulmasy DP, Snyder L. Substituted interests and best judgments: an integrated model of surrogate decision making. *JAMA* 2010;304:1946-7.
23. Sugarman J, Weinberger M, Samsa G. Factors associated with veterans' decisions about living wills. *Arch Intern Med* 1992;152:343-7.
24. Teno JM, Licks S, Lynn J, et al. Do advance directives provide instructions that direct care? SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. *J Am Geriatr Soc* 1997;45:508-12.
25. Teno J LJ, Wenger N, et al. Advance directives for seriously-ill hospitalized patients: effectiveness with the Patient Self-Determination Act and the SUPPORT intervention. *J Am Geriatr Soc* 1997;45:500-7.
26. Teno JM, Stevens M, Spornak S, Lynn J. Role of written advance directives in decision making: insights from qualitative and quantitative data. *J Gen Intern Med* 1998;13:439-46.
27. Schneiderman LJ, Kronick R, Kaplan RM, Anderson JP, Langer RD. Effects of offering advance directives on medical treatments and costs. *Ann Intern Med* 1992;117:599-606.
28. Hanson LC, Tulskey JA, Danis M. Can clinical interventions change care at the end of life? *Ann Intern Med* 1997;126:381-8.
29. Danis M, Mutran E, Garrett JM, et al. A prospective study of the impact of patient preferences on life-sustaining treatment and hospital cost. *Crit Care Med* 1996;24:1811-7.
30. Kass-Bartelmes BL, Hughes, R. Advance Care Planning : Preferences for Care at the End of Life. *Research in Action* 2003.
31. Pope TM. The maladaptation of Miranda to advance directives: a critique of the implementation of the Patient Self-Determination Act. *Health Matrix Clevel* 1999;9:139-202.
32. Doukas D. Advance directives in patient care: if you ask, they will tell you. *Am Family Phys* 1999;59:530-3.
33. Fagerlin A, Schneider CE. Enough. The failure of the living will. *Hastings Cent Rep* 2004;34:30-42.
34. Tillyard AR. Ethics review: 'Living wills' and intensive care--an overview of the American experience. *Crit Care* 2007;11:219.
35. Goodman MD, Tarnoff M, Slotman GJ. Effect of advance directives on the management of elderly critically ill patients. *Crit Care Med* 1998;26:701-4.
36. Faber-Langendoen K. A multi-institutional study of care given to patients dying in hospitals. Ethical and practice implications. *Arch Intern Med* 1996;156:2130-6.
37. Karlawish JH, Hall JB. Managing death and dying in the intensive care unit. *Am J Respir Crit Care Med* 1997;155:1-2.
38. Johnson RF, Jr., Baranowski-Birkmeier T, O'Donnell JB. Advance directives in the medical intensive care unit of a community teaching hospital. *Chest* 1995;107:752-6.
39. Kish Wallace S, Martin CG, Shaw AD, Price KJ. Influence of an advance directive on the initiation of life support technology in critically ill cancer patients. *Crit Care Med* 2001;29:2294-8.
40. Bradley EH, Rizzo JA. Public information and private search: evaluating the Patient Self-Determination Act. *J Health Polit Policy Law* 1999;24:239-73.
41. Virmani J, Schneiderman LJ, Kaplan RM. Relationship of advance directives to physician-patient communication. *Arch Intern Med* 1994;154:909-13.
42. Gordon NP, Shade SB. Advance directives are more likely among seniors asked about end-of-life care preferences. *Arch Intern Med* 1999;159:701-4.

43. Cohen-Mansfield J, Rabinovich BA, Lipson S, et al. The decision to execute a durable power of attorney for health care and preferences regarding the utilization of life-sustaining treatments in nursing home residents. *Arch Intern Med* 1991;151:289-94.
44. Morrell ED, Brown BP, Qi R, Drabiak K, Helft PR. The do-not-resuscitate order: associations with advance directives, physician specialty and documentation of discussion 15 years after the Patient Self-Determination Act. *J Med Ethics* 2008;34:642-7.
45. Ewer MS, Taubert JK. Advance directives in the intensive care unit of a tertiary cancer center. *Cancer* 1995;76:1268-74.
46. High DM. Why are elderly people not using advance directives? *J Aging Health* 1993;5:497-515.
47. Tulsky JA, Fischer GS, Rose MR, Arnold RM. Opening the black box: how do physicians communicate about advance directives? *Ann Intern Med* 1998;129:441-9.
48. Tulsky JA, Chesney MA, Lo B. How do medical residents discuss resuscitation with patients? *J Gen Intern Med* 1995;10:436-42.
49. Kolarik RC, Arnold RM, Fischer GS, Tulsky JA. Objectives for advance care planning. *J Palliat Med* 2002;5:697-704.
50. Quill TE. Perspectives on care at the close of life. Initiating end-of-life discussions with seriously ill patients: addressing the "elephant in the room". *JAMA* 2000;284:2502-7.
51. Roter DL, Larson S, Fischer GS, Arnold RM, Tulsky JA. Experts practice what they preach: A descriptive study of best and normative practices in end-of-life discussions. *Arch Intern Med* 2000;160:3477-85.
52. Fischer GS, Arnold RM, Tulsky JA. Talking to the older adult about advance directives. *Clin Geriatr Med* 2000;16:239-54.
53. Teno JM, Nelson HL, Lynn J. Advance care planning. Priorities for ethical and empirical research. *Hastings Cent Rep* 1994;24:S32-6.
54. Forrow L. The green eggs and ham phenomena. *Hastings Cent Rep* 1994;24:S29-32.
55. Gordon EJ, Daugherty CK. 'Hitting you over the head': oncologists' disclosure of prognosis to advanced cancer patients. *Bioethics* 2003;17:142-68.
56. Helft PR, Hlubocky F, Wen M, Daugherty CK. Associations among awareness of prognosis, hopefulness, and coping in patients with advanced cancer participating in phase I clinical trials. *Support Care Cancer* 2003;11:644-51.
57. Emanuel LL, Barry MJ, Stoeckle JD, Ettelson LM, Emanuel EJ. Advance directives for medical care--a case for greater use. *N Engl J Med* 1991;324:889-95.
58. Smucker WD, Ditto PH, Moore KA, Druley JA, Danks JH, Townsend A. Elderly outpatients respond favorably to a physician-initiated advance directive discussion. *J Am Board Fam Pract* 1993;6:473-82.
59. Tierney WM, Dexter PR, Gramelspacher GP, Perkins AJ, Zhou XH, Wolinsky FD. The effect of discussions about advance directives on patients' satisfaction with primary care. *J Gen Intern Med* 2001;16:32-40.
60. Ditto PH, Danks JH, Smucker WD, et al. Advance directives as acts of communication: a randomized controlled trial. *Arch Intern Med* 2001;161:421-30.
61. Wright AA, Zhang B, Ray A, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA* 2008;300:1665-73.
62. Coppola KM, Ditto PH, Danks JH, Smucker WD. Accuracy of primary care and hospital-based physicians' predictions of elderly outpatients' treatment preferences with and without advance directives. *Arch Intern Med* 2001;161:431-40.
63. Diem SJ, Lantos JD, Tulsky JA. Cardiopulmonary resuscitation on television. Miracles and misinformation. *N Engl J Med* 1996;334:1578-82.

64. Gehlbach TG, Shinkunas LA, Forman-Hoffman VL, Thomas KW, Schmidt GA, Kaldjian LC. Code status orders and goals of care in the medical ICU. *Chest* 2011;139:802-9.
65. Ott BB. Advance directives: the emerging body of research. *Am J Crit Care* 1999;8:514-9.
66. Curtis JR, Patrick DL, Caldwell ES, Collier AC. The attitudes of patients with advanced AIDS toward use of the medical futility rationale in decisions to forego mechanical ventilation. *Arch Intern Med* 2000;160:1597-601.
67. Teno J LJ, Wenger N, Phillips RS, Murphy DP, Connors AF Jr, Desbiens N, Fulkerson W, Bellamy P,, WA K. Advance directives for seriously ill hospitalized patients: Effectiveness with the patient selfdetermination act and the SUPPORT intervention. *J Am Geriatr Soc* 1997;45:500-7.
68. Mower WR, Baraff LJ. Advance directives. Effect of type of directive on physicians' therapeutic decisions. *Arch Intern Med* 1993;153:375-81.
69. Upadya A, Muralidharan V, Thorevska N, Amoateng-Adjepong Y, Manthous CA. Patient, physician, and family member understanding of living wills. *Am J Respir Crit Care Med* 2002;166:1430-5.
70. Danis M, Garrett J, Harris R, Patrick DL. Stability of choices about life-sustaining treatments. *Ann Intern Med* 1994;120:567-73.
71. Rosenfeld KE, Wenger NS, Phillips RS, et al. Factors associated with change in resuscitation preference of seriously ill patients. The SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. *Arch Intern Med* 1996;156:1558-64.
72. Ditto PH, Smucker WD, Danks JH, et al. Stability of older adults' preferences for life-sustaining medical treatment. *Health Psychol* 2003;22:605-15.
73. Morrison RS, Olson E, Mertz KR, Meier DE. The inaccessibility of advance directives on transfer from ambulatory to acute care settings. *JAMA* 1995;274:478-82.
74. Martin DK, Emanuel LL, Singer PA. Planning for the end of life. *Lancet* 2000;356:1672-6.
75. Tolle SW, Tilden VP, Nelson CA, Dunn PM. A prospective study of the efficacy of the physician order form for life-sustaining treatment. *J Am Geriatr Soc* 1998;46:1097-102.
76. Teno JM LS, Lynn J, Wenger N, Connors AF Jr, Phillips RS, O'Connor MA, Murphy DP, Fulkerson, WJ DN, Knaus WA. Do advance directives provide instructions that direct care? *J Am Geriatr Soc* 1997;45:508-12.
77. Teno JM, Lynn J, Phillips RS, et al. Do formal advance directives affect resuscitation decisions and the use of resources for seriously ill patients? SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. *J Clin Ethics* 1994;5:23-30.
78. Puchalski CM, Zhong Z, Jacobs MM, et al. Patients who want their family and physician to make resuscitation decisions for them: observations from SUPPORT and HELP. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. Hospitalized Elderly Longitudinal Project. *J Am Geriatr Soc* 2000;48:S84-90.
79. Kavic SM, Atweh N, Possenti PP, Ivy ME. The role of advance directives and family in end-of-life decisions in critical care units. *Conn Med* 2003;67:531-4.
80. Shalowitz DI, Garrett-Mayer E, Wendler D. The accuracy of surrogate decision makers: a systematic review. *Arch Intern Med* 2006;166:493-7.
81. Uhlmann RF, Pearlman RA, Cain KC. Physicians' and spouses' predictions of elderly patients' resuscitation preferences. *J Gerontol* 1988;43:M115-21.
82. Marbella AM, Desbiens NA, Mueller-Rizner N, Layde PM. Surrogates' agreement with patients' resuscitation preferences: effect of age, relationship, and SUPPORT intervention. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. *J Crit Care* 1998;13:140-5.
83. Corke CF, Lavery JF, Gibson AM. Choosing life support for suddenly severely ill elderly relatives. *Crit Care Resusc* 2005;7:81-6.

84. Fagerlin A. Projection in surrogate decisions about life-sustaining medical treatments. *Health Psychology* 2001;20:166-75.
85. Tilden VP, Tolle SW, Nelson CA, Fields J. Family decision-making to withdraw life-sustaining treatments from hospitalized patients. *Nurs Res* 2001;50:105-15.
86. Molloy DW, Guyatt GH, Russo R, et al. Systematic implementation of an advance directive program in nursing homes: a randomized controlled trial. *JAMA* 2000;283:1437-44.
87. Weeks WB, Kofoed LL, Wallace AE, Welch HG. Advance directives and the cost of terminal hospitalization. *Arch Intern Med* 1994;154:2077-83.
88. Chambers CV, Diamond JJ, Perkel RL, Lasch LA. Relationship of advance directives to hospital charges in a Medicare population. *Arch Intern Med* 1994;154:541-7.
89. Jacob DA. Family members' experiences with decision making for incompetent patients in the ICU: a qualitative study. *Am J Crit Care* 1998;7:30-6.
90. Abbott KH, Sago JG, Breen CM, Abernethy AP, Tulskey JA. Families looking back: one year after discussion of withdrawal or withholding of life-sustaining support. *Crit Care Med* 2001;29:197-201.
91. Vig EK, Starks H, Taylor JS, Hopley EK, Fryer-Edwards K. Surviving surrogate decision-making: what helps and hampers the experience of making medical decisions for others. *J Gen Intern Med* 2007;22:1274-9.
92. Zhang B, Wright AA, Huskamp HA, et al. Health care costs in the last week of life: associations with end-of-life conversations. *Arch Intern Med* 2009;169:480-8.
93. Edinger W, Smucker DR. Outpatients' attitudes regarding advance directives. *J Fam Pract* 1992;35:650-3.
94. Pfeifer MP, Sidorov JE, Smith AC, Boero JF, Evans AT, Settle MB. The discussion of end-of-life medical care by primary care patients and physicians: a multicenter study using structured qualitative interviews. The EOL Study Group. *J Gen Intern Med* 1994;9:82-8.
95. Teno JM, Lynn J. Putting advance-care planning into action. *J Clin Ethics* 1996;7:205-13.
96. Patrick DL, Pearlman RA, Starks HE, Cain KC, Cole WG, Uhlmann RF. Validation of preferences for life-sustaining treatment: implications for advance care planning. *Ann Intern Med* 1997;127:509-17.
97. Uhlmann RF, Pearlman RA, Cain KC. Understanding of elderly patients' resuscitation preferences by physicians and nurses. *West J Med* 1989;150:705-7.
98. Cohen-Mansfield J, Droge JA, Billig N. Factors influencing hospital patients' preferences in the utilization of life-sustaining treatments. *Gerontologist* 1992;32:89-95.
99. Coppola KM, Bookwala J, Ditto PH, Lockhart LK, Danks JH, Smucker WD. Elderly adults' preferences for life-sustaining treatments: the role of impairment, prognosis, and pain. *Death Stud* 1999;23:617-34.
100. Abraham JL. Advances in palliative medicine and end-of-life care. *Annu Rev Med* 2011;62:187-99.
101. Meier DE, Beresford L. POLST offers next stage in honoring patient preferences. *J Palliat Med* 2009;12:291-5.
102. Hickman SE, Hammes BJ, Moss AH, Tolle SW. Hope for the future: achieving the original intent of advance directives. *Hastings Cent Rep* 2005;Spec No:S26-30.
103. Respecting Choices. (Accessed at www.gundersenlutheran.com/eolprograms/)
104. Landro L. The informed patient: new efforts to simplify end-of-life care wishes. *Wall Street Journal* 2011.
105. MacGillis A. Debate Over End-of-Life Care Began in Small Midwestern Town. In: *The Washington Post*. Washington, D.C.; 2009.
106. Goodlin SJ. Palliative care in congestive heart failure. *J Am Coll Cardiol* 2009;54:386-96.
107. Goodlin SJ. End-of-life care in heart failure. *Curr Cardiol Rep* 2009;11:184-91.
108. Goodlin SJ, Hauptman PJ, Arnold R, et al. Consensus statement: Palliative and supportive care in advanced heart failure. *J Card Fail* 2004;10:200-9.

109. Chapman E, Landy A, Lyon A, Haworth C, Bilton D. End of life care for adult cystic fibrosis patients: facilitating a good enough death. *J Cyst Fibros* 2005;4:249-57.
110. Larson AM, Curtis JR. Integrating palliative care for liver transplant candidates: "too well for transplant, too sick for life". *JAMA* 2006;295:2168-76.
111. Reeder-Hayes KE. A piece of my mind: Way back when. *JAMA* 2011;305:2266-7.