

Advance Care Planning for Fatal Chronic Illness: Avoiding Commonplace Errors and Unwarranted Suffering

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Patients with eventually fatal illnesses often receive routine treatments in response to health problems rather than treatments arising from planning that incorporates the patient's situation and preferences. This paper considers the case of an elderly man with advanced lung disease who had mechanical ventilation and aggressive intensive care, in part because his nursing home clinicians did not complete an advance care plan and his do-not-resuscitate order did not accompany him to the hospital. The errors that led to his hospitalization and his unwanted treatment there demonstrate how the ordinary lack of advance care planning is deleteri-

ous for patients who are nearing the end of life. We discuss serious, recurring, and generally unnoticed errors in planning for care near the end of life and possible steps toward improvement. Repairing these shortcomings will require quality improvement and system redesign efforts, methods familiar from patient safety initiatives. Reliable improvement will also require making it unacceptable for clinicians to fail to plan ahead for care during fatal chronic illness.

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"Quality Grand Rounds" is a series of articles and companion conferences designed to explore a range of quality issues and medical errors. Presenting actual cases drawn from institutions around the United States, the articles integrate traditional medical case histories with results of root-cause analyses and, where appropriate, anonymous interviews with the involved patients, physicians, nurses, and risk managers. Cases do not come from the discussants' home institutions.

SUMMARY OF EVENTS

A 71-year-old man with worsening ventilatory failure and chronic obstructive pulmonary disease arrived by ambulance from his skilled-nursing facility to a hospital emergency department, where the staff intubated him and admitted him to the intensive care unit. This course was contrary to his previously stated wishes, but he had no specific or written advance care plan and his do-not-resuscitate order did not transfer with him.

THE CASE

Mr. Jan (a pseudonym), a 71-year-old man with severe chronic obstructive pulmonary disease and mild dementia, was convalescing at a skilled-nursing facility after a hospital stay for pneumonia. Mr. Jan developed increasing shortness of breath and decreasing responsiveness over 24 hours. The nursing facility staff called the emergency medical service, who found the patient unresponsive, with a respiratory rate of 8 breaths/min and oxygen saturation at 85% on room air. Although Mr. Jan had discussed his desire to forgo aggressive, life-sustaining measures with his family and nursing personnel, the nursing facility staff did not document his preferences, inform the emergency team about them, or mention his do-not-resuscitate order. After the emergency team was unable to intubate him at the scene, they inserted a nasal pharyngeal

airway, administered supplemental oxygen, and transported the patient to the emergency department of a second hospital.

Mr. Jan remained unresponsive. He was afebrile, with a systolic blood pressure of 190 mm Hg, a heart rate of 105 beats/min, a respiratory rate of 8 breaths/min, and an oxygen saturation of 88% despite supplemental oxygen. He had diminished breath sounds without wheezes, and a chest radiograph showed large lung volumes without consolidation. Arterial blood gases showed marked respiratory acidosis. The emergency department physician wrote, "full code for now, status unclear." The staff intubated and sedated Mr. Jan and transferred him to the intensive care unit.

Paramedic: [Mr. Jan] was laying there exposed [when we arrived at the nursing facility]; there was no bracelet or necklace letting us know that he might be something different than a full code. I didn't ask the question, and it was not told to me.

THE ERROR OF UNWANTED TREATMENT

Mr. Jan's experience falls within the Institute of Medicine's definition of error: "failure of a planned action to be completed as intended" (1). The nursing home staff failed to inform the emergency staff or the hospital of Mr. Jan's decision to forgo resuscitation. Mr. Jan's care was inappropriate but commonplace (2, 3). Providers do not regularly plan ahead or transfer plans across settings, a pattern that often yields unwanted treatments (4, 5). When we presented this case to approximately 250 physicians at a hospitalist conference, 80% reported that less than one quarter of their patients with severe emphysema had a written advance care plan that would be available in the emergency department and that specifically addressed resuscitation and ventilator use.

An obvious starting point for assessing Mr. Jan's situ-

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ation might be: “Why was his order against resuscitation not given to the emergency responders?” However, his problems began much earlier: “Why wasn’t a comprehensive plan prepared for the foreseeable worsening of Mr. Jan’s condition?” and “With many hours of decline, why weren’t the patient, his family, and his physician consulted much earlier in the day?”

ADVANCE CARE PLANS AND ADVANCE DIRECTIVES

Although Mr. Jan did have an order against attempting resuscitation and had expressed his preferences, he did not have a comprehensive, specific, and documented advance care plan (6, 7). This mistake may not strike clinicians as being as obvious as a medication error (8) or the wrong patient undergoing a procedure (9); however, by failing to plan ahead in chronic lung failure and similar conditions, the health care system virtually ensures that treatment will not follow patients’ preferences once patients want palliative care rather than intubation and intensive care.

Commonly, advance directives address two issues: who should speak for the patient if he or she cannot (health care proxy or durable power of attorney for health care) and the kinds of treatments that should or should not be undertaken (living will or health care directive). Patients with serious chronic illness need a more comprehensive advance care plan that documents agreement among the patient, his or her loved ones, and the care team about how to respond to expected complications. Care plans should provide specific preparations, such as availability of medications or instructions about engaging family and clergy. The advance care plan supersedes the default plan to call for emergency transport to the hospital when the patient’s condition worsens. While advance planning includes decisions about attempting resuscitation, it also requires understanding the challenges of both living with the illness and its complications, as well as making choices about treatments (10, 11). For examples of useful care plans, see **Table 1**.

Although health care proxies and durable powers of attorney help to identify responsible surrogate decision makers quickly, they do not actually direct treatment decisions. Orders to forgo resuscitation only guide decisions for patients in cardiac arrest. Living wills generally use broad and imprecise language (12, 13), such as “no life-sustaining treatment when death is certain.” An advance directive that is vague or nonspecific will not decide treatment (12–14). With advance care planning that specifies what is to happen with various likely complications, patient satisfaction increases and costs may decline (15).

HOW TO GENERATE AN EFFECTIVE ADVANCE CARE PLAN

Patients with end-stage organ failure generally have a gradual physical decline punctuated by episodes of life-threatening exacerbations and complications (16). Like most patients with emphysema, Mr. Jan probably started

Table 1. Examples of Useful Care Plans

Generally limiting aggressive care. “I do not want to undergo more intensive care. Specifically, I direct that I have no more intubation or ventilator support. I am willing to have other treatments aimed to treat the causes of recurrences of shortness of breath. If those are inadequate, then I ask for medication to ease the struggle to breathe and to allow me to pass away peacefully. I hope to be able to stay at home, and I have enrolled in a home care hospice program. Please do not call 9-1-1 in an emergency. Call xxx-yyy-zzzz for the hospice program instead. Obviously, I have an order to forgo resuscitation and the state’s standard wristband to indicate that decision.”

Wanting fully aggressive treatment but with some limits. “I know that I have emphysema and that it will eventually take my life. However, I want to live as long as possible and I am willing to go through a great deal to stay alive. Please call 9-1-1 if I am struggling to breathe and cannot call for myself. I have a continuous positive-pressure breathing mask at home and my wife knows how to apply it. Please call her or my physician (Dr. R. at sss-ttt-vvvv) if I am sick. I am willing to go through intensive care and ventilator support, so long as there is any chance that I can come home again. However, if I have permanently lost my ability to relate to others or to know myself (by a stroke or brain damage, for example), then I’d ask that you turn to my wife, who has my durable power of attorney for health care. She knows that I intend to stop life-sustaining treatment at that point.”

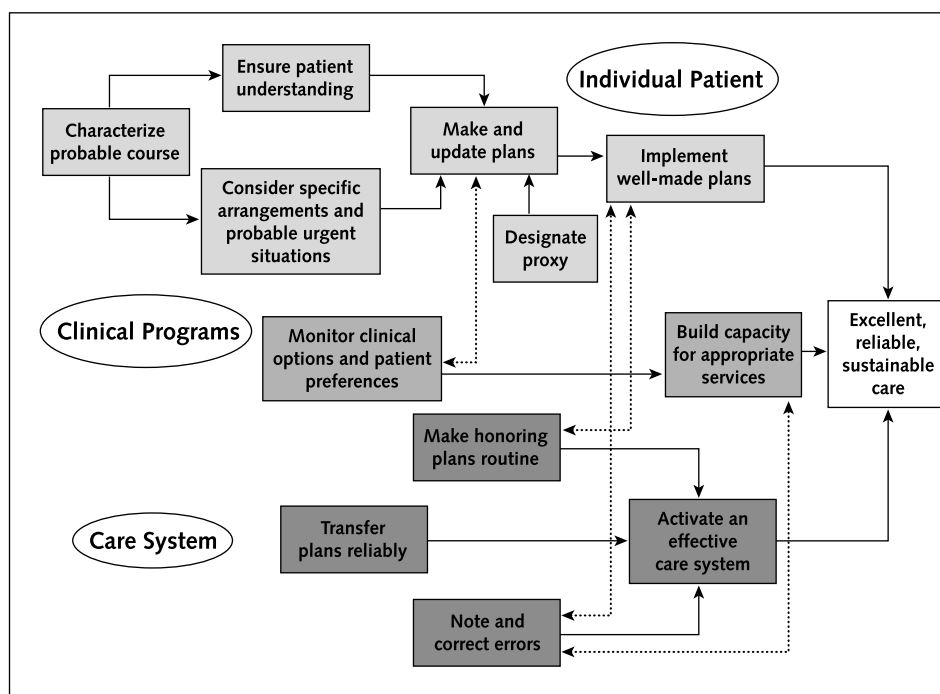
Having other (unusual) priorities. “I know that my life is coming to an end sometime soon. I have given my son John the authority to make decisions about my care and treatment, and I expect my doctors and others to let him take care of me as he sees fit. I am writing here to be sure that everyone involved understands that my view of religion requires that I die as aware as possible. I aim to seize this opportunity to gain insight and wisdom. Thus, do not aim to keep me comfortable, if doing so would blunt my experience of my body and its transition to eternity. Even if I appear to be in anguish, I believe that God does not give us anything we cannot take, and I trust that His meaning will be apparent to me at that time.”

his week feeling fairly well, in his usual state of health, with no warning of the serious episode upcoming (17). Physicians cannot predict when a patient like Mr. Jan will deteriorate or which episode will be fatal. In one study, on the day before death for patients with severe obstructive pulmonary disease, the predicted median chance of surviving 6 months was 20%; just 1 week before death, the predicted median chance of 6-month survival was still 40% (18, 19). Thus, the care plan should ordinarily address both possibilities simultaneously: survival with ongoing disability and risk for death, as well as dying during this episode (18).

Clinicians can target advance care planning by asking themselves, “Would I be surprised if this patient died within the next 6 months?” (20). When the patient is sick enough to die, advance care planning is a high priority (**Figure**). Generating an advance care plan requires tailoring how clinicians raise the issues to match the specific situation of the patient. Very little results from asking, “Do you want everything done?” One effective start is to ask, “What makes you happy in this part of your life?” and then to deal with topics such as setting goals, resource use, emotional and spiritual issues, and communication needs (20), using the patient’s language and priorities.

Even before Mr. Jan left the first hospital, he and his family, and the care teams at the hospital and the skilled-nursing facility that would next provide care, should all

Figure. Elements essential to reliable, high-quality care for patients with fatal chronic illness.



have agreed on a workable plan for the next exacerbation. Since Mr. Jan did not want intubation and hospitalization again, a workable plan has to ensure that the nursing home staff can relieve his dyspnea on-site, with medications and staff ready to provide sedation if needed, instead of automatically calling for emergency transfer to the hospital. When we presented Mr. Jan's case at the hospitalist conference, less than 1% of the clinicians stated that they routinely offered advance care plans that specified terminal sedation instead of emergency ventilator support to patients with severe obstructive lung disease; however, 98% would choose terminal sedation for themselves in similar circumstances. Clearly, patients should be able to have the course that physicians want for themselves. For a patient who does not want intubation and intensive care, the patient's provider team must be ready to provide terminal sedation for suffocation (20). Failing to do so would force the patient either to die with suffocation, a grim way to die, or to have his wishes ignored by having intubation and intensive care unit treatment (21).

Ensuring that appropriate care is available where Mr. Jan lives might require selecting a different nursing facility, engaging the help of hospice, or ensuring that capable physicians will cover his needs within the facility. If the nursing home team was unfamiliar with managing emphysema at the end of life, they could consult with a physician or nurse skilled in palliative care or help Mr. Jan enroll in hospice. If a skilled-nursing facility has no way to provide for patients with emphysema, then a patient like Mr. Jan should not go there. The hospital clinicians must find out

whether a proposed discharge destination can provide essential services before approving transfer.

Medicare will not pay hospice to serve patients during a postacute stay in a skilled-nursing facility, so Mr. Jan could not have had skilled-nursing facility and hospice care at the same time. This restriction in eligibility for services needs to shape discharge planning and probably to generate advocacy for reform, but the patient's clinical team must stay responsible for arranging for care that reliably meets the patient's needs.

THE CASE, CONTINUED

The intensive care unit physicians ordered broad-spectrum antibiotics and nebulized bronchodilators for exacerbation of chronic pulmonary disease. Someone contacted the patient's son, who arrived at the hospital several hours later. The son was the first person to inform the staff that Mr. Jan had already concluded that, "in a state where he . . . needed the extraneous support to be kept alive, he didn't want it." Checking with the nursing facility staff revealed Mr. Jan's order against resuscitation.

Despite being confident of his father's wishes to forgo aggressive interventions, Mr. Jan's son struggled with deciding whether to withdraw treatments already initiated. Mr. Jan's son felt that the decision to withdraw life-sustaining treatment was very different from the decision to withhold it.

Intensive care unit attending physician: This was really, really difficult for the son. . . . He knew

very clearly this was not what his [father] wanted. He saw [him] in the intensive care unit, intubated, with a [nasogastric] tube, with central lines, and a Foley catheter and the whole full court press of supportive measures. But again, [Mr. Jan] was also stabilized and his oxygenation was better. The son was incredibly torn as to what step to take.

STRATEGIES TO SUPPORT PATIENTS AND FAMILIES

Some people might contend that no one was harmed because Mr. Jan survived with intensive interventions, but this view overlooks important facts. Patients and family members should be able to trust that clinical teams will implement thoughtful decisions made in advance. Mr. Jan suffered discomforts that he did not wish to face, and he may have lost dignity he had hoped to preserve. The errors incurred costs and suffering without remedy and should have been prevented.

While ethicists and lawyers contend that withholding and withdrawing treatment have the same moral significance (22, 23), most family members feel the weight of responsibility differently. Specific clinical strategies can ease the family's experience when deciding whether to stop treatments. The care team should structure and document every life-sustaining treatment as a time-limited trial. Tube feeding, steroids for increased intracranial pressure, ventilators, and every other life support measure should entail scheduled re-evaluations, with the possibility of discontinuing that support. Sometimes it is charitable to the family for the team to stop adjusting or adding treatments rather than to confront deliberate withdrawal. However, when withdrawal is best, the responsible physician can ease the family's burden: "I expect him to die soon. Stopping the ventilator will be better than waiting for the next complication." This approach allows the family to make sense of their role in consenting, without feeling overwhelmed by personal responsibility for the death. Family members often struggle to make sense of their role in this unfamiliar situation and worry about whether they "did the right thing." Many family members later recall how important supportive words were (for example, a nurse saying that they were doing a good job or recommending what a family member might do in such a situation).

Failure to treat symptoms adequately at the end of life is a serious medical error. Mr. Jan's plan of care requires combining symptom relief with treatment of his underlying disease (24, 25). Hospital-based palliative care consult teams can often provide useful expert advice (26). Steroids and diuretics are important, but opioids might also help to decrease chronic dyspnea, often without carbon dioxide retention (27–29).

Since people living with eventually fatal chronic illness will have exacerbations and eventually die, plans directing how to respond should be in place. In Mr. Jan's case, the various hospitals, skilled-nursing facility, and emergency

Table 2. Strategies To Improve Care of Patients with Eventually Fatal Chronic Illnesses

Enrolling in or leaving any program of care (hospital, home care, nursing facility, or hospice) should routinely lead to reviewing and documenting advance care plans. Facilities should audit rates and work toward 100% completion and transfer of plans. Medicare and other payers could compensate at a higher level those institutions that achieved this goal.

Patients living with eventually fatal chronic illness should have a care team that stays with them through all settings. Facility-based clinicians can play important roles, but the continuity clinicians must remain involved since they know the patient, family, and living arrangements across time.

Direct care staff that the family comes to know and trust should continue through difficult times, rather than switching with every change in payer.

Documented plans should be available and understood across settings. Computerized records accessible from multiple locations may be the best method, but telephone calls, wristbands, and written records can be effective.

Emergency care providers should regularly ask about advance care plans when serving very sick patients at home or in nursing facilities.

medical system are all part of one functional care system, yet the people involved probably have never considered how to ensure good care across time and sites. They probably have different, and potentially inconsistent, ways of dealing with these situations and no way to monitor their combined effectiveness or learn from mistakes (Table 2, Figure).

THE CASE, CONTINUED

Mr. Jan's son needed time to think through the situation and talk with family members, so the medical team continued aggressive support. The next day, Mr. Jan became more responsive but remained confused. His pulmonary status improved, and the team decreased sedation. Mr. Jan became very agitated and began pulling on his endotracheal tube.

After much discussion, Mr. Jan's son agreed to a plan to wean Mr. Jan from mechanical ventilation slowly, over a 24-hour period. Once Mr. Jan was extubated, the physicians would not reintubate him for any reason. However, Mr. Jan continued to be agitated, and slow weaning would have required restarting sedation. Therefore, the family and the ICU staff decided to extubate Mr. Jan immediately.

Mr. Jan's son: We visited him the following morning. . . . We didn't see any changes in his condition. When we came back [from brunch], the whole story changed . . . because he had woken up and was basically trying to extubate himself. . . . He was pretty sure of his wishes. When he got [the endotracheal tube] out, he seemed to be back to normal . . . and within hours . . . was acting as if nothing happened. Surprisingly he had [a] very strong appetite, cracking jokes, and . . . he kept on saying that he wanted to go home.

The hospital staff learned from the nursing facility records that Mr. Jan had been considering hospice. After a few days of hospitalization, Mr. Jan went to a second skilled-nursing facility and later enrolled in hospice. He died 2 months later without any further transfers. The nursing facilities, the hospitals, the physicians, and the emergency medical team did not pursue quality improvement activities to address errors in Mr. Jan's care.

Mr. Jan's son: [When he was discharged to the skilled-nursing facility,] I made sure that the [do-not-resuscitate] documentation was there and that it was sure to be followed thereafter. Even though I was glad that he came back, I didn't want him to go through that again.

CHARACTERISTICS OF A HIGH-PERFORMANCE SYSTEM OF CARE FOR ADVANCED ILLNESS

Most Americans now die while old and sick and after a substantial period of disability. Until just the last half-century, in contrast, most people died before reaching old age and were not particularly sick until shortly before death. The care system does not yet match our new demographics. Mr. Jan had been in the care of two hospitals, a skilled-nursing facility, and the emergency medical team. If he survived this episode, he faced another nursing facility, hospice, and possibly hospitalizations before dying. Ideally, all sites would consider themselves part of one system and would pride themselves on collaboration to deliver top-quality, timely, and efficient services in accordance with patients' wishes (30). In reality, the various programs do not communicate with each other, nor do they take responsibility for measuring and achieving excellent care across settings. No one measures outcomes, determines patterns of care, or provides feedback.

One way to envision a better system is to aim for arrangements that would allow clinicians to promise patients the care elements that matter, from onset of serious illness to death (20, 31), and to pursue improvements across a region. When mistakes occur, responsible providers should investigate how to prevent repetitions. Every care provider, from hospitals to home care, should report problems across institutional boundaries and ensure that they do not afflict future patients. However, of the more than 250 clinicians present at the hospitalist conference, less than 20% worked in a setting with guidelines shared with other providers in the region or with any procedures to identify or resolve shared problems.

Nevertheless, an advance care plan established early in his course should follow Mr. Jan, with updating, through to death. Advance care plans could be on an electronic registry or otherwise passed along from one provider to the next. In many of the Veterans Affairs medical centers and Kaiser Permanente, such computerized integration and document flow is under way (20). In addition, changes in

legislation could encourage clinicians and emergency medical teams to rely on the patient's statements to supplement formal written documents (32).

HOW TO IMPLEMENT RELIABLE AND EFFECTIVE ADVANCE CARE PLANNING

Current practice accepts the errors in Mr. Jan's case as usual practice, and this stops reform before it starts (20). Every involved provider should label these events as true medical errors and investigate them with the same vigor and "root-cause analysis" harnessed for other mistakes (8, 9).

How can this be accomplished? First, clinicians can make substantial gains by fomenting quality improvement within their organizations (20, 30, 33). Second, the staff who share many patients as they move through hospital, nursing facility, emergency medical system, and home care could work together to implement and monitor changes until the system works reliably (20, 30). Effective, appropriate advance care plans implemented across sites and time should be one quality indicator for judging care for vulnerable patients (34).

In one illuminating case, a nursing home patient with a missing advance care plan was admitted and treated overly aggressively at Oregon Health Sciences University Hospital, Portland, Oregon. The hospital staff viewed it as a serious medical error; they filed the appropriate reports, engaged the nursing facility staff, and changed the system's performance (35). More than 90% of nursing home residents in Oregon have some advance care plans, so the error was more obvious than it would be elsewhere.

Other improvement projects for patients with chronic fatal illness have used advance care planning. In Oregon, special bright pink forms inform emergency workers of patients' wishes for end-of-life care (3, 36). Providers in LaCrosse, Wisconsin, created effective community-wide advance care planning: 85% of decedents had an advance directive, 95% of these were in the medical record, and in 98% of the deaths, life-sustaining treatment had been avoided in accordance with the patients' wishes (20). The Veterans Administration Health System initiated incentives, monitoring, and technical support and raised the percentage of seriously ill patients covered by advance directives from 50% to nearly 70% within 3 months (20). Further examples of quality improvement initiatives can be found in the Appendix (available at www.annals.org).

While clinician performance is important, regulations, financing, and service delivery arrangements must also improve (25, 37). If Mr. Jan had not been hospitalized, Medicare would not have paid more for the additional nursing time and medications, so the nursing facility would have lost money. The emergency responders, hospital physicians, and hospital would not have been used or paid. The proper course of care would have saved Medicare money and saved Mr. Jan and his family from suffering and abrogation of self-determination, but every provider

would have earned less (38). Reform would undoubtedly accelerate if Medicare paid half of the usual rate for repeat hospital admissions for serious chronic emphysema with no advance care plans or if better compensation accompanied skilled-nursing facility stays with advance care plans or palliative care consultations.

Ultimately, addressing the errors in Mr. Jan's care does not falter for lack of creative possibilities but rather from lack of recognition across systems that the care was inappropriate, that the errors harmed the patient and his family, and that ensuring patient safety through reliable advance care planning is a priority. Re-engineering payments and regulations may take substantial time, but effective advance care planning for those living with advanced, progressive, and eventually fatal chronic illness could be the standard of care within weeks—including seamless transfers across time and settings. The fundamental element needed is commitment to the enterprise.

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But Dan Lynch raised his beer again. He was whispering, his voice fierce. "I just don't think it credits a man's life to say he was in the clutches of disease and that's what ruined him. Say he was too loyal. Say he was disappointed. Say he made way too much of the Irish girl and afterwards couldn't look life square in the face. But give him some credit for feeling, for having a hand in his own fate. Don't say it was a disease that blindsided him and wiped out everything he was." He bit off a drink, his face flushed. "Do the man that favor, please."

Alice McDermott
Charming Billy
New York: Random House, Delta Trade Paperbacks; 1999:23

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APPENDIX

Other Sources of Information

For information on death and dying, consult Lynn and Harold's *The Handbook for Mortals* (Oxford Univ Pr; 1999). For electronic resources, see www.growthhouse.org.

For information on quality improvement, consult Lynn, Schuster, and Kabacoff's *Improving Care for the End of Life: A Sourcebook for Health Care Managers and Clinicians* (Oxford Univ Pr; 2000). For electronic resources, see www.medicaring.org.

For information on health care policy and fatal chronic diseases, see www.abcd-caring.org.

Questions and Answers from Grand Rounds Presentation

Dr. Robert M. Wachter (Moderator), Quality Grand Rounds editor: Can we talk about the DNR [do-not-resuscitate] bracelets? Some worry about stigmatizing patients.

Dr. Lynn: We need reliable, quick identification that patients find acceptable. Some states are using only bracelets or necklaces and some states are using only a form. In Oregon, everyone in the EMS [emergency medical service] system knows where to look for the advance directive—on the refrigerator on a bright pink piece of paper. Of course, an efficient electronic information system could do the same without annoying patients and family. We don't actually know which is the most reliable and acceptable, but that's a very straightforward piece of research. Some teams give patients a special folder with the advance care plan and emphasize, "Be sure that *anytime* you see *any* doctor *anywhere*, you show them this." Even that approach works more than 90% of the time.

A physician from Iowa: Probably 50 to 70% of my patients complete a living will, but some patients would see Mr. Jan's experience as a 2-month extension of life and would want to go on a ventilator. Very few would actually say, "No, please just give me sedation and let me die."

Dr. Lynn: Almost everyone in almost every setting *eventually* wants to have treatment stopped. There aren't very many people who prefer to die in an ICU on a ventilator with multiple system failure. In a care system that can offer very good home care, there does not need to be any bias toward deciding to stop. The only necessary bias is toward having a clear decision. I know of hospice and home care teams that can have a skilled nurse at a patient's home within an hour, anytime, day or night. They can get better care to the patient faster than the EMS system, and patients are comfortable staying home. If dying with suffocation is the only option, patients have to "choose" the emergency department.

A physician from Idaho: I perceive a problem among physicians and nurses of equating DNR status with "no care."

Dr. Lynn: This is a serious problem. The generalizing of the DNR order makes it less possible to use DNR orders correctly. I never write solely a DNR order. For example, I write what's important to this patient now are the following things: here's how to manage pain, what to do for shortness of breath, how to assist the family, and among other things, if this patient has

cardiac arrest, do not initiate resuscitation. Articulating the overall plan seems to reduce harmful generalizing of the DNR.

A physician from California: Let's take a patient that has metastatic lung cancer and is demented and the family insists on "doing everything." Is there any way to stop?

Dr. Lynn: Just 50 years ago, almost no patients lived like this. Families are still unclear about what constitutes virtuous behavior in this setting. Remember that 90% of the time or more, good counseling, getting their own minister in, and getting a family meeting together really does work. Only a small group, for whatever reason, just can't make plans that acknowledge mortality. You finally have to decide whether to yield to their priorities and provide treatments that do not serve the patient well, although you can usually keep the patient from suffering badly. Otherwise, you really have to argue it out in order to protect the patient. "Doing everything" is almost always contrary to a patient's well-being and usually signifies a family that is trying hard to be valiant in defense of a family member. Addressing and respecting the family's role usually helps to bring about accord.

A physician from California: Is there any initiative to make advance care planning an essential part of residency training or medical school curriculum?

Dr. Lynn: The Education for Physicians on End-of-life Care Project (EPEC), an AMA [American Medical Association] program, has a module on end-of-life planning*. We still don't have a system that provides a context for this work. If a trainee generates a terrific advance care plan, the odds are that he will never know how things turn out. What happens downstream needs to get fed back to the trainee so that the education can affect behavior.

A physician: What happens when the spoken words regarding DNR contradict the written words? Does the new spoken word take precedence?

Dr. Lynn: Statements of a reasonably competent patient clearly take precedence.

Dr. Sanjay Saint (Presenter), Quality Grand Rounds editor: How can hospitalists do a better job of ensuring that an advance care plan is made?

Dr. Lynn: Hospitalists can develop skills in these conversations, when patients are stable enough to have them, even on a ventilator. You should make it a personal goal that people with serious chronic illness do not leave your care without an advance care plan. I have proposed, at least half seriously, that the second time a patient with severe emphysema is admitted to the same hospital and has no advance care plan, the hospital should get only half of the DRG [diagnosis-related group] payment. That would make reform happen quickly. Also, see yourself as part of the continuum of care. You might be seeing this particular patient for the first time, but if his doctor regularly sends you patients like this, you should know the doctor. Hospitalists should welcome outside continuity providers as respected partners in decision-making. Finally, we need regional systems that

*Note: The California legislature has enacted AB 487, which requires all California physicians to complete 12 hours of continuing education in pain medicine and end-of-life care by December 2006. Exceptions to the requirement are physicians in the specialties of pathology and radiology. Further information can be found at www.medbd.ca.gov/cmclaws.htm or www.sfms.org/sfm/sfm202e.htm.

work. For example, we can develop an IT [information technology] system so that plans are available to any urgent-care provider in a city.

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