

Engaging Seriously Ill Older Patients in Advance Care Planning

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Case Objectives

- Define advance care planning and goals of care discussions.
- Recognize when it is appropriate to engage patients in advance care planning discussions.
- List the consequences of inadequate communication and planning for care at the end of life.
- Discuss how to improve the quantity and quality of end-of-life communication and decision making.

The Case

A 94-year-old woman with history of congestive heart failure (CHF), hypertension, and gout presented for a routine primary care visit to a new physician, an intern in the local training program. She had been seen in the housestaff clinic for more than 10 years by a series of residents, each handing over her care to a new intern at the end of their residency. Her previous resident had recently graduated.

The intern reviewed the patient's chart and discovered that the patient lived alone, walked mainly with a cane, and was able to manage all of her activities of daily living independently. She did have severe hearing impairment and could not read or write (she never learned literacy skills). Notably, in the last year the patient had been hospitalized 5 times for CHF exacerbations or pneumonia. She had experienced a clear functional decline in the previous 3 months.

In reviewing the medical record, the intern discovered the patient's code status in the hospital and in the clinic had always been documented as "full code." The intern was surprised to see that there was no documentation of any in-depth discussions of the patient's wishes. Given the patient's comorbidities and recent decline, the intern was quite concerned that she was at very high risk for becoming seriously ill and requiring aggressive life-sustaining measures.

During their first visit, the intern asked, "Has anyone ever talked with you about what you would want if you got so sick that you needed artificial life support to survive?" The patient answered, "You know, no one has

ever asked me about that. I guess I always figured the doctors would just do what is right."

The intern performed a more detailed chart review and spoke with the patient's daughter. He discovered no evidence that any health care provider had ever engaged in advance care planning with the patient.

Concerned about the possible harm the patient could experience, the intern and his supervisor engaged the patient in a thoughtful discussion of her wishes. Ultimately she stated clearly she would not want full resuscitation, mechanical ventilation, or any other aggressive artificial life-prolonging measures. She told them with a smile and a wink, "Hey, when it's my time, I'm fired up and ready to go!"

The Commentary

by Daren K. Heyland, MD, MSc

This case centers around an older patient whose advance care wishes were not known to her providers—because they hadn't asked.

Advance care planning (ACP) is a communication process wherein people plan for a time when they cannot make decisions for themselves.⁽¹⁾ It includes reflection, deliberation, and determination of a person's values and wishes or preferences for treatments at the end of life. These determinations are generally made outside of the clinical context and should not be viewed as a specific medical decision. Medical decisions require consideration of wishes, values, and preferences associated with a specific medical intervention. ACP may include communication about these values and wishes with an individual, his or her loved ones, future substitute decision maker(s), and health care provider(s). It may result in the naming of a person to make decisions for the patient, should he or she become incapable, which frequently happens when older patients approach the end of life.⁽¹⁾ This communication process may also result in a written expression of wishes and preferences (advance care plans), although verbal or other expressions are also useful. In some health care systems, these wishes or plans may be further codified in the form of written instructional directive or living will (specific instructions for treatments to be used or not used, or choices for future medical care). The (dis)utility of these specific documents has been previously discussed. The remarks herein pertain strictly to the aforementioned ACP process, not instructional directives. In contrast to ACP, goals of care discussions are more formalized interactions between providers and patients that adhere to health care laws (which vary by state), including rules about surrogate decision making and informed consent, and they help determine whether life-sustaining treatments are used.

There is emerging literature on the benefits of ACP but also the impact of its absence, as illustrated in this case. One study found that patients who had prepared advance care plans or who had been engaged in end-of-life conversations with their physicians received care that was strongly associated with their preferences, and the majority preferred limited care or comfort care.⁽²⁾ In contrast, when physicians and patients or families failed to engage in ACP, there was more intensification of care (use of intensive care units, life-sustaining technologies, or feeding tube insertions) and less use of hospice services.⁽³⁾ Consequently, the absence of ACP or end-of-life conversations was associated with poorer patient ratings of quality of life in the terminal phase of the illness, lower ratings of satisfaction by the family during the

terminal illness, and increased family ratings of anxiety and depression.(3,4) Finally, the literature suggests that ACP can significantly reduce health care costs during the final week of life.(5)

Ideally, ACP should occur in primary care or community settings with all patients, but advance planning is especially important among those who have advanced medical illness and their families (and/or substitute decision makers). We recently developed an audit tool that enabled us to assess the degree to which patients have engaged in key ACP activities and whether health care professionals had accurately elicited the values and preferences of their patients.(6) We found that, for the most part, health care professionals failed to adequately engage older, seriously ill hospitalized patients in end-of-life conversations.(7) Most of the older patients surveyed (76%) had thought about end-of-life care and 89% had discussed it with family or friends. Almost half (48%) of patients had completed an advance care plan and 73% had formally named a surrogate decision maker for health care. However, of patients who had discussed their wishes with others, only 30% had done so with their family doctor and only 55% with any member of the health care team in the context of their current admission. Agreement between expressed preferences for the patient's end-of-life care and prescribed orders in the hospital record was only 30% for patients and 31% for family members.(7) We went on to define this end-of-life communication problem as a serious medical error. Of patients who had previously expressed a preference not to have cardiopulmonary resuscitation, 35% had orders in the hospital to receive it (as with the patient in this case).(8) We further noted that there was considerable variability (range: 14%–82%) in the potential for overtreatment rates across sites. Finally, in this multi-institutional study, 15% of these older hospitalized patients did not have any documentation regarding the use of life-sustaining treatment in their chart.(8) In most health care systems, this would, by default, mean they would be resuscitated if they had a cardiopulmonary arrest. If these resuscitative efforts were not consistent with their treatment preferences, this would be an additional source of medical error.

Such medical errors have significant potential for harming patients (and their families) and are inconsistent with patient-centered care. When asked why they had not discussed these matters with their doctors, patients and families essentially asked, "If it was an important topic, why isn't the doctor bringing up the subject?"(9) Patients and families also reflected their sense that they were "not sick enough" or the timing for this discussion was not right.

Engaging in ACP is complicated. It is not as simple as just asking patients what treatments they want (or don't want) at the end of life. A recent analysis suggests that patients are not grounded in authentic values or aware of what is really important to them, and their values do not relate to their expressed preferences in any clinical or statistical sense.(10) Moreover, older patients are often ill-informed about treatment options at the end of life.(11) It is clear patients may benefit from more support with decision making, and there is evidence that ACP tools, including ones that clarify values and help with decisions, are effective and should be implemented in our health care system.(12,13)

However, despite our best efforts to adequately prepare patients in advance for clinical decision-making encounters (13), if health care providers don't engage patients to elicit their treatment preferences, high rates of end-of-life communication errors will continue. In a recent study, we surveyed hospital-based clinicians to elicit barriers to having such conversations with their patients. Clinicians identified patient and family factors that hinder goals of care discussions, such as difficulty accepting a poor prognosis, trouble understanding the limitations of life-sustaining treatments, and disagreement between family members

about goals of care.⁽¹⁴⁾ Although the patient in this case had not previously engaged in end-of-life discussions, her providers were able to document her preferences when she was relatively healthy, before any unnecessary interventions occurred. Taking steps to prepare patients and families for these decision-making encounters may reduce barriers for clinicians to engage in these end-of-life conversations with older patients.

Given the magnitude and prevalence of the problem, a system-based approach, geared to the needs of individual clinical areas, may be necessary to address the communication and documentation failings highlighted by this case. Such an approach would include: (i) ongoing audits of communication, decision-making, and documentation practices in local settings to define the severity of the problem and highlight opportunities for improvement; (ii) embedding decision support tools by nonphysician facilitators to help prepare patients for clinical decision-making encounters with physicians; (iii) systematic training and tools for clinicians to aid them in improving their communication and decision-making skills; and (iv) standardizing order sets to enable accurate documentation of medical orders of life-sustaining therapies that are transportable across the system. Examples of such tools can be found on the resource page of the CARENET website (www.thecarenet.ca). Finally, at a health care system level, quality indicators for end-of-life communication and decision making have been developed and validated and may inform additional initiatives to further enhance the quality of end-of-life care.⁽¹⁾

Take-Home Points

- Patients need more support in end-of-life decision-making, and a variety of tools exist to help clarify their values and inform their preferences.
- Failure to engage in appropriate advance care planning should be deemed a medical error.
- Clinicians need to be aware of the high prevalence of medical errors related to end-of-life communication and their significant attendant consequences on patient, family, and health system outcomes.
- Implementation of system-wide quality indicators and institutional audits may enable identification of problems and opportunities for improvement in end-of-life care in this vulnerable patient population.

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