Advance care planning is an art, not an algorithm

The article by Drs. Messinger-Rapport et al in this issue of the Cleveland Clinic Journal of Medicine makes several assertions about advance care planning with which I disagree. As a practicing oncologist and hospice medical director in a community setting for almost 20 years, I believe the authors’ attempt to reduce a complex physician-patient interaction to a practice algorithm oversimplifies the issues.

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INTUITION, EXPERIENCE, AND TRAINING PLAY A VITAL ROLE

I agree with the authors that advance care planning is an oft-mentioned but under-performed function of being a physician in current American society. Our nation has become a people who deny physical vulnerability, frailty, and death. This area is not well taught in our medical schools and residency training programs.

However, the algorithms in the paper do not effectively address the timing and process of advance care planning. It is clearly not effective to have an end-of-life discussion at the bedside of a critically ill patient about to be intubated. It also seems futile to have a superficial discussion with patients about advance care planning at a time when they are healthy and in the setting of a routine and brief office visit. In this healthy population, the episodic discussions recommended by the authors could become background noise and could seem irrelevant to a patient. Physicians are already overburdened with responsibilities. Re-educating society that lives are not infinite is a social issue that needs to begin early in our lives.

In any setting, a social history, properly taken, should identify family structure, responsible next of kin, and family issues of discord that could affect treatment decisions and patient care. This is all that is needed as a minimal discussion about advance care planning.

Once patients develop significant illness, speaking to them about advance care planning becomes more relevant to their lives. As patients struggle with their illnesses and physical decline, the opportunity for further discussion grows and the impact of these interventions becomes greater. The energy and time it takes to have such discussions are better spent in these settings.

Discussing long-term planning with a patient is where intuition, experience, and training play a vital role. The balance between the pragmatic need for advance care planning and the need for allowing the patient to have hope of wellness is difficult to achieve and different for every patient, every family, and every care situation. It is for this reason that I find the flowcharts outlined in the paper difficult to follow and not very useful for the care of patients. Given the diversity of patients for whom we care, it seems impossible to me to condense the subject down to a care-flow matrix. This is an area in which the art of patient care and the art of being a physician come fully into play and cannot be replaced by an algorithm. Individual and small-group training with mentors, at all levels of medical education, would allow a physician to grow in
comfort and skill in dealing with advance care planning.

**LIVING WILLS CAN BE USEFUL**

Another point on which I disagree with Dr. Messinger-Rapport et al is their assessment of the utility of the living will. They state that a living will applies only to patients who are terminally ill or in a persistent vegetative state. However, I find that it can also supply important information at all stages of illness. While it may lie “dormant” in a legal sense, it can give important information for a family by providing a window into the patient’s state of mind as it relates to the patient’s willingness to limit care in certain settings. Once a patient is able to articulate situations that warrant limiting care, a surrogate decision-maker (or the patient) can try to broaden those limits. It is up to the physician to articulate prognosis so the patient and family can decide how much they are willing to do to maintain that limited level of function. Any treatment can be declined at any time during a patient’s life or illness.

The living will also provides a framework in which to discuss end-of-life issues with a patient. It can open the discussion about current quality of life as perceived by the patient and what level of medical treatment the patient is willing to pursue. As the authors note in their article, those desires are fluid and can change over time. This does not render the living will useless. It shows that the living will needs to be adapted over time to suit the patient’s current situation.

The authors describe a patient with Alzheimer disease for whom a percutaneous endoscopic gastrostomy tube was recommended by a physician but declined by his wife. They assert that a living will does not offer guidance in this situation, since the patient was not, strictly speaking, terminally ill. I disagree. Medical care can delay death for years. If the patient’s quality of life is poor, that delay may violate the implied wishes of the patient and should be discussed. Before he became severely demented, the patient may not have wanted to have his life prolonged if the end result was a continued decline in his already compromised quality of life. The family should have been given that option to consider.

**RE-EDUCATING PEOPLE ABOUT LIFE, ILLNESS, AND DEATH**

Advance care planning is an essential component of being a physician and taking care of patients. A broad movement needs to be undertaken to re-educate people about the realities of life, illness, and death. The training of our physicians about advance care planning should begin early and should be continued throughout their medical education and careers. One-on-one or small-group mentoring would be an ideal method of training. The attempt to develop an algorithm to guide those discussions tries to simplify a process that is extraordinarily complex. Each situation is different and requires well-developed skills and practiced and mentored intuition. Experience and the art of being a physician cannot be reduced to a “model approach” or a flowchart.