

Why the Patient Self-Determination Act Has Failed

Dee Leahman

Deciding when and how to cross the bridge from curative to palliative care is both complicated and simple. Complicated by clashes in perspective and values: Opinions differ as to what is best for the patient, how quality of life should be defined, who is best qualified to make these important decisions.

Simple? Sometimes as simple as asking, “What would the patient want?” But what if they can’t express themselves?

Over a decade ago the Patient Self-Determination Act (PSDA) was passed. If designed to give patients the right to refuse unwanted treatments before the fact so that tragedies like the family of Nancy Cruzan and Terri Schiavo faced would disappear, then the PSDA has not worked.

“Why are we still dying in places we would not choose, in ways we do not want, surrounded by strangers, our wishes undocumented, unknown and, therefore, often not honored?”

Today, only about 30% of Americans have advance directives. Living Wills are the simplest, most common and least effective type. Healthcare Powers of Attorney require that you appoint a healthcare agent, tell that agent which treatment options you would choose under what circumstances, document your choices and wishes, make sure all the right people have copies of the document... Whoa!! Talk about complicated. Most people respond: “We’ll get around to that later—when we need it.” Discussion deferred.

As Dr. Laura Hanson points out in this edition’s lead article,¹ “Patients and their families say they prefer terminal care at home, but four of five deaths in the United States take place in hospitals and nursing homes.” In other words, about 80% of us would rather die in a home-like setting, but that only happens 20% of the time. What we say we want is NOT what we get. Why are we still dying in places we would not choose, in ways

we do not want, surrounded by strangers, our wishes undocumented, unknown and, therefore, often not honored?

A cancer patient who was active in her church taught me the answer. Asked if she had talked with her doctor about her disease, she replied: “Oh, no! He’s much too busy.” I asked, “What about your minister?” “Lord, no,” she replied. “This kind of talk makes him really uncomfortable.” Her perceptions may not have been accurate but they kept her from helpful information and support she needed.

I agree with Dr. Hanson when she says “patients generally welcome these conversations, and many are willing to record their wishes in some form.” I also believe that most patients, physicians, and family members are reluctant to *initiate* the conversation. Once given permission and some coaching, discussion flows freely. But permission to talk about these care options is often implicitly denied.

Most of us know clearly what kind of treatment we want near life’s end. Few of us are comfortable and skilled when approaching the subject. Avoiding discomfort now, we invite confusion, conflict, and permanent damage to relationships later. Documented wishes are often too vague to be of much help once patients cannot speak for themselves. The only fail-safe I know is thorough and early conversations about these tough decisions.

We have failed in implementing the Patient Self-Determination Act because we have allowed documents to speak for us, and paper can’t talk. We don’t say the right things to the right people at the right time in the right place. We have failed both organizationally and personally.

Organizationally

Organizations receiving Medicare funding are mandated to distribute advance care documents and information about them. *Wrong place!*

Information about living wills and healthcare powers of

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attorney is given to patients upon admission to healthcare facilities along with a mix of other material about the facility. *Wrong time!*

Healthcare facility admissions personnel seldom have time to facilitate in-depth advance care planning discussions and often don't have answers to questions that should be asked. *Wrong person!*

Admissions staff ask, "Yes or No: Do you have an advance directive?" Most of the time that is translated to the easier default: "Do you have a Living Will?" Healthcare Powers of Attorney are more complicated and confusing. Time is limited. Seldom is the patient asked to identify their healthcare agent. Most patients don't bring a copy of the document with them. Many medical records that have the "yes" box marked do not contain copies of advance care documents that are easy to access and understand. Even completed documents clearly marked on the medical record do not give physicians much direction. They are often vague and open to interpretation. That is not a good thing in the presence of difference of opinion. *Wrong mechanism!*

Personally

Focus has been on documents rather than on the all-important conversation. Time, skill, and comfort level are in short supply all around when talking about treatment options and end-of-life care decisions. Parents don't want to upset children; children don't like talking to their parents about life's end. Patients expect the physician to bring it up. Physicians hope the patient will. In short, the conversation doesn't happen, at least not in the way it should.

The Carolinas Center for Hospice and End of Life Care, in collaboration with the North Carolina AARP and the Life's End Institute in Missoula, Montana, conducted a survey of North Carolina AARP members that revealed interesting facts about the way they approached (or did not approach) discussions about end-of-life care.

Ninety-two percent of respondents reported they wanted honest answers from their physician; 88% wanted to understand treatment options; 74% feared dying painfully. Even so, only 11% had spoken to their physician about their concerns.

Eighty-three percent said it is very important to be at peace spiritually (this number was 93% among African American respondents); 62% said it is very important to have comfort from spiritual or religious persons. Still, only six percent had talked with their clergy about these issues.

What an Incredible Disconnect!

Instead of using the documents as a catalyst to promote conversation, they have been used as a shield to protect us from having the conversation. The formal documents leave out the personal touch.

Two of my most memorable conversations about advance directives and end-of-life care, one with an aging relative, the other with my closest friend, taught me a lot about how important

the details of the conversation can be and how void of meaning and direction the documents alone are.

Mamie was practically blind and deaf. She knew she didn't have much longer to live. She was bed ridden and dependent on others but mentally alert. As we talked about her future, she said, "I can't hear, I can't see. I can hardly move. But I can still smell. Can we get some flowers and scented candles in here?" I couldn't find that request anywhere in her formal documents.

I asked my friend: "What's on your list of the kind of care you'd like near the end of life?" He said quickly and matter-of-factly, "I want my pain controlled. I'd like to be with people I love. And I want music."

"Fine," I said. "I can help make that happen." We changed the subject. A few days later I realized I had failed to ask something important: What *kind* of music did he want? I assumed I knew, knowing what he listened to all the time. I asked, "Classic Rock, right?" He replied, "No, Celtic Harp." Lessons learned: it's in the details; ask the right questions.

You would think that healthcare professionals would have protected themselves and those they love by selecting a healthcare agent and documenting their wishes. They will have expressed to their agent and those in their important "inner circle" details about the setting, care, treatment options, and personal details they'd like someone to handle when they can no longer speak or act for themselves. Knowing that such a conversation makes it more likely that their wishes will be honored, they will have recorded their wishes and made them easily accessible to the right people. Not so. A clear majority of most audiences of physicians, nurses, social workers, clergy, and attorneys I speak to have not adequately dealt with these issues.

I maintain that it is difficult, if not hypocritical, to encourage patients to do advance care planning unless we have done it ourselves. It is appalling that so many of us are willing to subject our patients, our families, and ourselves to "pot luck" when it comes to end-of-life care.

So What Can We Do?

- 1 Normalize the conversation. Talk about the taboos early, prior to diagnosis or crisis. Ask about the kind of care they want. Take enough time or make a referral to someone who can.

I like the familiar model of the "consult." If my primary care physician discovers I have a cardiac problem, she calls for a cardiac consult. If I'm in respiratory distress, she may ask for a pulmonary consult. Why not call for an advance care planning consult if a patient needs assistance discussing and documenting one's end-of-life care wishes?

- 2 With terminal diagnoses, help the patient and family redefine hope. Rather than avoiding the truth, creating false hope, and delaying the inevitable, help patients and families focus on hope for comfort and maximizing quality of remaining life. As Dr. Hanson points out, identifying the point in time to transition from curative to palliative care and helping the

patient and family manage that transition well is one of the central dilemmas of end-of-life care. I like her mention of compassionate communication. She states, *“Absent this skill, physicians will be unable to help patients decide on appropriate treatments, assess physical symptoms, or address emotional and spiritual suffering. Meaningful and compassionate communication is the core skill in end-of-life care. Patients facing the crisis of their own mortality require time to express fears and to seek reassurance of physician attention to their needs, in addition to medical aspects of their care.”*

- 3 Use the documents as a vehicle to foster discussion about treatment options and preferences rather than viewing them as the desired outcome
- 4 Encourage policy change by sponsoring consumer and physician-friendly statutes such as Oregon’s POLST (Physician Orders for Life-Sustaining Treatment) or West Virginia’s POST (Physician Orders for Scope of Treatment). Become a process improvement activist in institutions having difficulty with advance directive documentation, tracking, and education. Help create an organization recognized for patients’ wishes being known, documented, and honored wherever possible.
- 5 Spend time talking with patients’ families about the whole person, not just the medical components of the disease. An unsolicited, positive outcome of this kind of trust-building dialogue is risk reduction. Well informed families who feel the physician has been caring, compassionate, and open are less likely to litigate.
- 6 Help “relocate” advance directives. Move them out of the acute care setting and “upstream” to physicians’ offices, ministers’ studies, estate planning sessions with attorneys, and kitchen table conversations.
- 7 Break the barrier of silence by bringing the subject of advance care planning into routine intake and assessment appointments. Add questions related to selection of a healthcare proxy to paperwork completed during the initial visit.

Linda Lewis, former hospice chaplain and currently Project Coordinator for *Faith In Action* End of Life Care Ministries at the Hospice & Palliative CareCenter in Winston-Salem, North Carolina, sums it up well:

“What used to be the moment of death when life ended fairly abruptly and quickly, has now become, in many cases, the season of death. Ventilators, feeding tubes, artificial hydration, dialysis, and even antibiotics can prolong the inevitable, meaning that the dying process may take weeks or months, or as in Terri Schiavo’s case, even years.”

The dialogue has to be more than, “I don’t want to live like a vegetable.” What is it that makes life meaningful? What would I want my family and other decision-makers to know about me should I be unable to communicate my wishes? Encouraging people to complete Advance Directives is important, but these documents are of little use unless open and reflective conversation has taken place with those who may be faced with making crucial decisions in a time of crisis.

This is not just about “autonomy,” the ethical principle that has guided most of the discussion around these issues in recent years. It is not just about “what I want.” Who will be the one to speak for me when I cannot speak for myself? What does that person need to know about my values and my feelings about life? How can I have conversations now that will pave the way for wholeness and community when a crisis occurs? Personal wishes need to be discussed in the context of community, recognizing that others will be involved in carrying out wishes and will be affected by decisions that are made. Meaningful conversations with loved ones before a crisis not only help make medical decisions easier down the road; they can also strengthen relationships and create bonds as life values are shared openly and honestly.”

Too many people are dying in ways they would not choose simply because they did not talk about it ahead of time. Physicians can only honor patients’ wishes if they know what those wishes are. Encourage the conversation.

REFERENCES

- 1 Hanson, LC. Palliative Care: Innovation in Care at the End of Life. *North Carolina Medical Journal* 2004;65(4): 202-208.