

Getting the Treatment You Want: Is Anyone Listening?

By Anne Montgomery

Many of us – tens of millions, in fact – are on track to live into our 80s and beyond. Scientific breakthroughs accompanied by improved public health programs in many countries have led to rising longevity in industrialized countries and elsewhere. In the United States, however, there are also clear signs of chaos. Often patients do not have access to the full range of treatments they want, or their wishes are ignored and they receive unwanted medical treatment. Multiple hospitalizations during the last year of life are common¹ and many may be unnecessary² and/or unwanted. Invasive and costly treatments are a frequent result — though many older adults and those with advanced illness also suffer from under-treated pain.³

Major challenges remain in figuring out how to provide patient-centered, high-quality health care for those in advanced old age and those who are younger but very ill. The health care system is not well organized to provide consistent, reliable support to older adults who know and are able to express how they want to approach the end of their lives. Studies show that even when treatment preferences are recorded – in advance directives, living wills and other types of statements – they may be misinterpreted⁴ or overridden.⁵ And some argue that overtreatment can rise to the level of elder abuse when an older adult's expressed wishes at the end of life are ignored.⁶

Altering these dynamics will require a series of straightforward conversations about the cultural context in which patients live and the legal and ethical imperatives health care professionals face. Ideally, these conversations would be accompanied by a clear understanding of a patient's legal rights that assure autonomy and choice, and include

an understanding of how individual choices can best be communicated in everyday life. They would focus on the need to document and carefully interpret patient and surrogate wishes across various medical settings, and lead to forward-looking strategies that proactively incorporate patient treatment decisions into the operations of evolving systems of care.

More specifically, greater awareness is needed about:

- Principles of patient-centered decision-making based on informed consent as a key component of good end-of-life care;
- How some health care systems have altered their treatment protocols for individuals with advanced illness, and how this success can be recognized and measured;
- Steps that the federal government can take to promote public and provider education about unwanted medical treatment;
- How advance directives and other legal tools can best be used to protect patients' wishes and treatment preferences; and
- Additional legislative and administrative strategies to improve treatment at the end of life.

To be successful, conversations about these issues will require strong commitment, close cooperation and a desire to forge consensus across a variety of stakeholders – the physician and nursing communities, religious leaders, family organizations, hospice and palliative care organizations, long-term care providers, those working to advance the interests of older adults, representatives of the legal and

bioethics communities, advocates for the terminally ill and disease-specific organizations, and the input of ordinary Americans, especially older adults. These conversations could result in careful and thoughtful shifts in medical practice, including the underlying vitalistic philosophy of medicine⁷ that prevents many physicians from foregoing treatment they believe is in the patient's best interest.

Law and Policy

Principles of bioethics, a series of court decisions and state and federal law all support patient autonomy and self-determination. The Patient Self-Determination Act (PSDA), a federal statute enacted in 1990, requires that health care institutions participating in Medicare and Medicaid – including hospitals, nursing homes, managed care plans, hospices and home health agencies – must inform patients of their rights upon admission. Based on principles of informed consent, the law specifically requires institutions to inform patients in writing that they can: 1) accept or refuse treatment as permitted under state law; 2) execute an advance directive in accordance with relevant state law; and 3) receive information about an institution's policies on the withholding or withdrawing of life-sustaining treatments. In addition, the PSDA requires institutions to educate their employees and the general public about patient rights, as well as opportunities for drafting and signing advance directives. Finally, the law also gives the Secretary of Health and Human Services the authority to withhold payment from institutions that do not follow these requirements.

While the PSDA's requirements appear to be straightforward, there have been numerous problems in implementation. First, health care providers often notify admitted patients of their rights in a perfunctory manner that falls short of an educational and informed shared decision-making process. Second, most Americans have not prepared an advance directive.⁸ Third, studies show that individual doctors in private practice – who are not bound by the PSDA – have a difficult time fulfilling the law's intent. It is often difficult, for example, for physicians to translate the legal language used in advance directives into clear and actionable medical orders. Also, conflicts sometimes arise between what patients say they want (or do not want) in advance directives and what a surrogate decision-maker requests. There may also be disagreement among surrogates.⁹ Finally, a person with an advanced illness or nearing the end of life would likely be better served by considering their treatment options earlier, appointing a health care

agent, and giving that agent (and the primary physician) as much guidance about his or her health care goals and preferences as possible.

Recent Developments

Over time, additional policy has been developed, but not without difficulty. In 2009, the health care reform proposal introduced by Representative John Dingell (D-Michigan) and approved by the House of Representatives, included policy authorizing Medicare reimbursement for physician counseling on advance directives (once every five years). This policy was originally crafted by Representative Earl Blumenauer (D-Oregon), a steadfast champion and pioneer of policy on unwanted medical treatment. However, misplaced concerns that such counseling could lead to “death panels” that would deny wanted treatment ultimately lead to this provision being dropped in the final version of the Affordable Care Act. The Obama Administration did publish a final rule promulgating criteria for Medicare “wellness visits” that included coverage for “voluntary advance care planning,” but dropped the policy after nine days due to political opposition.

Finally, in December 2011, the administration was able to finalize regulatory changes based on an earlier April 2010 White House memorandum. The memo directed the Dept. of Health and Human Services (HHS) to issue guidance underscoring the need for “all hospitals participating in Medicare or Medicaid to ensure that patients' advance directives, such as durable powers of attorney and health care proxies are respected, and that patients' representatives otherwise have the right to make informed decisions regarding patients' care.”¹⁰ Although the President's memorandum did not stipulate similar guidance on advance directives for nursing facilities, the Centers for Medicare & Medicaid Services in March 2013 revised the rules for state survey agencies that are charged with inspecting Medicare and Medicaid-participating nursing homes.¹¹

There are interesting differences between the hospital and nursing home documents. Whereas the hospital guidance does not mention advance care planning, the nursing home guidance states that “whether or not the resident chooses to execute an advance directive, discussion and documentation of the resident's choices regarding future health care should take place during the development of the initial comprehensive assessment and care plan and then periodically thereafter. The process of having such discussions, regardless of when they occur, is sometimes referred to as

‘advance care planning.’” According to the nursing home guidance, the ability of a dying person to control decisions about medical care and daily routines is “one of the key elements of quality care at the end of life.” Whether or not a resident has executed an advance directive, the guidance states, an individual that declines treatment, “may not be treated against his/her wishes. If a resident is unable to make a health care decision, a decision by the resident’s legal representative to forego treatment may, subject to State requirements, be equally binding on the facility.”

The more minimalist guidance for hospitals requires them to establish policies and procedures that assure a patient’s right to request or refuse treatment and indicate such a request will be addressed. However, hospitals are not obligated to fulfill a patient’s request for a treatment or service that a responsible physician believes is either medically unnecessary or inappropriate. The document further states that the patient may “provide guidance as to his/her wishes concerning provision of care in *certain situations*” [emphasis added]. And it notes that while a “hospital’s advance directive policy” is required to be provided only when individuals are admitted as inpatients, institutions should “also provide the advance directive notice to outpatients (or their representatives) who are in the emergency department, who are in an observation status, or who are undergoing same-day surgery.”

Care Planning Act of 2013 and Personalize Your Care Act

It was against this policy backdrop, that Senators Mark Warner (D-VA) and Johnny Isakson (R-GA) recently introduced the Care Planning Act of 2013. The proposal takes a deliberately comprehensive approach to rationalizing services provided to individuals in advanced old age. Below are some of the major features of the bill, which amends the PSDA and would apply to both Medicare and Medicaid. The bill has been referred to the Senate Finance Committee, but no action has been scheduled. In the House, Representative Blumenauer introduced the Personalize Your Care Act – a similar though more narrowly focused bipartisan bill that amends Medicare and Medicaid to cover voluntary advance care planning; directs HHS to expand and enhance POLST programs (an approach to end-of-life planning that emphasizes patients’ wishes about the care they receive and documents them in the form of a medical order); requires that advance directives and POLST forms be part of electronic health record development; and that advance directives developed in one state be recognized by other states as “authentic expressions” of a patient’s wishes.

Concluding Observations

Honest conversations among patients, providers and family members are needed to understand what an individual may want during advanced illness and at the end of life. Equally

Care Planning Act of 2013¹²

- Establishes Medicare and Medicaid reimbursement for health care professionals to engage in a voluntary and structured discussion about the goals and treatment options for individuals with serious illness, resulting in a documented care plan that reflects the informed choices made by patients in consultation with members of their health care team, faith leaders, family members and friends.
- Tests new models of intensive services for those with advanced illness, and provides funding to support the development of a public information campaign to encourage effective care planning. Provides grants to develop materials and maintain a web site with information about advanced care planning, portable treatment orders, palliative care, hospice, and planning services.
- Directs that providers identify evidence of patient preferences, such as directives from other states or past discussions about treatment goals, and requires documentation of plans made prior to discharge from health facilities to assure that care plans travel with patients after discharge.
- Directs HHS to develop quality metrics that will measure synchronicity among the individual’s stated goals, values, and preferences with documented care plans, the treatment that is delivered, and the outcome of treatment.
- Creates a Senior Navigation Advisory Board, comprised of a diverse range of individuals including faith leaders, health care professionals and patient advocates to monitor and advise HHS.

honest conversations must be held between policymakers and stakeholders to ensure that individuals get the care they want, but not more. It is time to develop a multi-pronged strategy that focuses on the consistent promotion of a patient's right to informed consent and self-determination in all major services settings, while at the same time identifying and preventing unwanted medical treatment. The starting point for achieving these goals is to get a clear commitment to intensive provider education and engagement, along with broad dissemination of patient decision aids. The time may now be ripe for a consumer-driven movement to shift physician behavior and health care system action.

Endnotes

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