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Ensure adequate end-of-life health care

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By Dr. David R. Grube, Guest columnist

My mom paid a painful price for not completing an advance directive about her preferences for end-of-life medical care. She was an intelligent and organized woman who had everything in her and my dad's life planned out and written down. She even drafted her own obituary. Ironically, she never discussed her end-of-life care goals with my father or her physician son (me), preferring to talk about "more pleasant subjects."

As a result, after she developed colon cancer at age 86, my dad and I had to figure out how to treat her post-surgical medical complications of heart and renal failure. She died in hospice care after prolonged, unbearable and unnecessary suffering. It broke both my dad's heart and mine.

Unfortunately, my mother's story is all too common. Nearly one out of four older Americans (24 percent) say that either they or a family member have experienced excessive or unwanted medical treatment, the equivalent of about 25 million people, according to a poll conducted last year by Purple Strategies. A key reason for this problem is only about one out of six Americans (17 percent) say they've had discussions about their end-of-life healthcare goals, preferences and values with a doctor or other healthcare provider, according to a recent Kaiser Health Tracking Poll.

Evidence-based research overwhelmingly shows the need for more and higher-quality doctor-patient conversations about the patient's healthcare goals, preferences and values. The report "Dying in America" by the Institute of Medicine noted that:

"Most people nearing the end of life are not physically, mentally, or cognitively able to make their own decisions about care ... The majority of these patients will receive acute hospital care from physicians who do not know them. As a result, advance care planning is essential to ensure that patients receive care reflecting their values, goals, and preferences."

One important step that should facilitate advance care planning is the Centers for Medicare & Medicaid Services' (CMS) recent decision to reimburse doctors, starting Jan. 1, 2016, for communicating with patients about their preferences and values about end-of-life care.

As a next step, we urge CMS to stop reimbursing health care professionals for providing unwanted medical treatment that directly violates a patient's documented end-of-life care goals.

In addition, we encourage Congress to take additional steps to ensure that Americans get the end-of-life treatment they want. They include:

- Establish federal payment for palliative care consultations with healthcare providers who will advocate for and support the values and choices of the patient with an advanced illness or nearing the end of life.
- Ensure that there are enough trained palliative care professionals to provide this service.
- Ensure advanced illness care encompasses access to an interdisciplinary care team, such as board-certified hospice and palliative care physicians, nurses and social workers.
- Allow patients the option of enrolling in hospice while continuing to receive disease-specific and restorative treatments if patients still want them.

Absent these health care reforms, poor understanding of treatment options and/or lack of acknowledgement of the extent of the illness may lead to inadequate planning, dissatisfaction with the process, unnecessary medical treatment and loss of quality of life.

Dr. Grube is a board certified physician in family medicine and is a national medical director for Compassion & Choices, www.compassionandchoices.org, the nation's oldest and largest end-of-life choice advocacy organization.

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