

Potential Impact of Advance Directive Law Act 169 on Decisions and Care for Patients at End of Life: Reflections of Ethics Consultants

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Patients' participation in end of life treatment decisions has received increasing attention in recent years as legal, ethical, and social pressures combine to support a more active role for patients. Despite overwhelming societal support for the view that individual patients should be involved in treatment decisions at the end of life, many problems remain in implementing this perspective.

Ethical and legal guidelines support the individual's role in medical decision making at end of life, including decisions to forgo life-sustaining treatment, even when it may result in death. Advance directives, such as living wills, were legislated in 1991 with the Patient Self-Determination Act (PSDA) and were aimed at strengthening the rights of patients to continue to express their wishes regarding the use of life-sustaining measures should they become terminally ill or permanently unconscious.^{1,2} In the years since that legislation was enacted, however, a number of studies have demonstrated that only a small percentage of patients have advance directives, and these percentages are even smaller among minority patients.^{3,4} However, Teno, in a national mortality follow-back survey (N=1587) 10 years after the enactment of PSDA, found that a huge 71% of the 1,587 people who died (at home, in nursing home, or in hospital) were said to have had an advance directive. Further, individuals who had an advance directive were less likely to have a feeding tube, or use a respirator in the last month of life compared with those who did not.⁵

On November 30, 2006, Act 169 (The General Assembly of Pennsylvania Senate Bill No. 628 session of 2005) was signed into law by Pennsylvania Governor Ed Rendell. This Act, like most laws, is the culmination of a process of negotiation and compromise. It includes some changes designed to assist providers, specifically around advance health care directives and health care decision making for patients incapable of directing care.

In the new law, advance directives are valid now when the patient is determined to be incompetent, is permanently unconscious, or has an end-stage medical condition. Incompetency is defined as: A condition in which an individual—despite being provided appropriate medical information, communication supports, and technical assistance—is documented by a health care provider to be unable to: 1) understand the potential material benefits, risks, and alternatives involved in a specific proposed health care decision; 2) make that health care decision on his own behalf; or 3) communicate that health care

decision to any other person. In the past, the term “terminal” was linked to a 6-month prognosis which meant that some patients with stroke and Alzheimer’s patients did not meet that requirement and thus were excluded from “benefiting” from having their documented wishes followed. To its credit, the new law streamlines the process for declaring a patient to be permanently unconscious or for being in an end stage condition, no longer requiring confirmation by a second physician.

Of distinction in the PA law is that artificial nutrition and hydration (AN/H) is given heightened attention. Rather than consider this on equal terms with other life-sustaining treatments that can be foregone, AN/H are not considered as a presumed treatment to be withheld or withdrawn unless the patient specifically states otherwise in writing. Thus, the new law seems to imply a legal obligation to continue AN/H unless stipulated by the advance directive. At the same time, the text indicates that families and providers may be able to discern a patient’s wishes regarding AN/H, if it can be derived from other information about that patient, and withheld or withdrawn based on those inferences.

In another notable aspect of the law, the new term “health care representative” is introduced to refer to a class of potential decisionmakers for decisionally-incapable patients. These are individuals who do not need to be formally designated (unlike a health care power of attorney), but are assumed to be determined through family lines to close friends. These individuals can also consent to ongoing treatment and forgoing of medical care. However, unlike the health care agent with a health care power of attorney document, health care representatives, according to this law, can only provide consent to forgo medical care when the patient meets the living will requirements; that is permanently unconscious and in end-stage disease.

The obligation of health providers to offer care that is more beneficial than burdensome and to provide comfort care at end of life is one that challenges many of us involved in ethics consultation and care of patients at end of life. Futile care is highly controversial because of the lack of consensus about whom or what defines futile care. The current Act reiterates that health care providers are not required to provide futile care but should “in general” have consent to withhold or withdraw care considered to be futile.

Where the new statute falls short of meeting the ethical needs of patients and health care providers “in the trenches” relates to its silence about serving the needs of the most vulnerable cohort of patients, those lacking decision making ability and having no advance directive or available family members or others who know their values. There are no easy answers; as Veatch has described, “alone, incompetent and dying” is as bad as it gets.⁶ Ideally for these patients, a court appointed guardian seems reasonable, but is impractical due to expense and time. Too often a patient dies before a guardian can decide and advocate for the patient. Further, the guardians appointed often assume the minimalist role of merely giving consent for continued treatment and intervention without any consideration of whether that for which they consent serves any human need for the patient. Patients lacking decision makers cannot be enrolled in hospice programs, where such high quality end-of-life care would be delivered. The law would be far more valuable to these patients lacking decision making ability were it to acknowledge the

reality that where no judgment can be made of the patient's values, including looking for substitute markers of values such as religious preference, retreat to a 'best interest' standard, with balance of proportionate benefits to burdens for the patient, is more likely to result in improved quality care at the end of life.

While the notion of autonomous decision making is one that is challenged daily in clinical settings across the country as decisions are made for dying patients by others, there is still an underlying societal belief in the importance of individual dignity and the rights of individuals to have a say in their medical treatment. Ensuring that medical care at end of life reflects respect for persons and supports a peaceful and dignified death remains a formidable challenge for policy makers and healthcare providers.

References

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