

Improving end-of-life care: Lessons from 40 years of work

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After four decades of work - first on patients' rights, then on family and caregiving relationships, and most recently on systemic reform—we now know that it will take additional efforts in all three areas to improve care at the end of life, concludes an [article](#) in the *New England Journal of Medicine*.

Although there has been progress in improving care near the end of life, early "optimism that the establishment of [patients'](#) legal and ethical rights to make decisions about their own care would lead to more appropriate end-of-life treatment faded in the face of sobering data showing that declaring these rights was not enough to alter treatment patterns and that systemic issues loomed large," write three experts on [end-of-life care](#) in an article in the February 12 issue of the *New England Journal of Medicine*.

The article is by Susan M. Wolf, Nancy Berlinger, and Bruce Jennings, the authors of *The Hastings Center Guidelines for Decisions on Life-Sustaining Treatment and Care Near the End of Life* (Oxford University Press, 2013). The book is a revised and expanded edition of *The Hastings Center's groundbreaking 1987 guidelines*.

Wolf is McKnight Presidential Professor of Law, Medicine & Public Policy at the University of Minnesota and principal author of the 1987 guidelines; Berlinger is a research scholar at The Hastings Center who directed the multi-year research project that supported the Guidelines revision; and Jennings is director of bioethics at the Center for Humans

and Nature, a senior advisor to The Hastings Center, and an author of the 1987 guidelines. Wolf and Jennings are also Hastings Center Fellows.

The article assesses 40 years of intensive effort to improve care of patients as they approach death, identifies the successes achieved and lessons learned, and proposes strategies for continued progress. "This history has demonstrated the need to attack the problem at all levels, from individual rights to family and caregiving relationships to institutional and health systems reform," the authors write.

They divide the history of work on improving end-of-life care into three stages:

- **Securing Rights (1976-1994).** Court cases and ethics guidelines established the rights of patients to refuse unwanted life-sustaining treatment and the authority of surrogates to refuse care on behalf of patients who were not competent to make decisions. Securing these rights was part of the effort in the early days to curb overtreatment at the end of life and to improve the dying process.
- **Facing Clinical Realities (1995-2009).** Although the establishment of patients' rights and the option to use advance directives was necessary, it was not enough. Empirical studies found that patients' wishes often were not honored. Studies also identified barriers to patients receiving palliative care and hospice. The second stage of work involved intensive efforts to improve caregiving relationships and realities. The politics of end-of-life care became particularly divisive in 2009, when opponents of the Affordable Care Act (ACA) made the false assertion that a proposed provision to reimburse physicians for discussing end-of-life planning with patients would create "death panels."

- Reforming End-of-Life Care Systems (2010-). With the passage of the ACA in 2010, "efforts to improve end-of-life care have become increasingly focused on health care institutions, systems, and finance." For example, there are now efforts to fund conversations between physicians and patients for end-of-life care and planning. Ethics initiatives have also become more system-focused. The updated Hastings Center Guidelines, for example, addresses not only individual rights and the clinical realities of decision making but also institutional and systemic issues such as transfers between institutions and the role of cost in decisions.

The article concludes with recommended strategies to continue progress in improving end-of-life care:

First, clinicians can be trained in the communications skills needed to help patients and their surrogates make informed decisions about care near the end of life.

Second, systemic improvements can be designed to assist all professions involved in caring for patients who are facing decisions about life-sustaining equipment or nearing the end of life. For example, clinicians should have access to at least generalist palliative care training.

Third, systemic and financing reforms should be enacted. The authors cite current incentives that work against dying patients' choices, interest, and safety, such as referrals of dying patients to the intensive care unit for dialysis, the nonbeneficial use of feeding tubes in patients with end-stage Alzheimer's disease, and late hospice referrals for patients with cancer.

"More work is needed at all levels - to protect patients' rights to choose

care options, to improve the quality of clinical care and clinicians' responsiveness to patients and families, and to create well-functioning health care finance and delivery systems that make high-quality care genuinely available," the authors conclude. They call on federal, state, and organizational authorities to formulate standards that support this progress, and for health care leaders, administrators, and clinicians to identify and address persisting care problems within their organizations. "The millions of Americans facing life-threatening conditions deserve no less."

Provided by The Hastings Center

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