

Penn bioethicist calls on researchers for more evidence-based end-of-life care programs

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Although the public and private sectors are currently engaged in an unprecedented array of efforts to improve end-of-life care, too many of these programs are not evidence-based, according to a scholar from the Perelman School of Medicine at the University of Pennsylvania. Writing in the *New England Journal of Medicine*, Scott Halpern, MD, PhD, associate professor of Medicine, Epidemiology, and Medical Ethics and Health Policy, says that despite recent federal decisions that signal a renewed interest in improving end-of-life care, investigators and research sponsors must be more involved to "identify, develop and rigorously test interventions so they can offer guidance" on implementing programs that work among the terminally ill.

In his commentary, Halpern says if end-of-life care policies were approached in the same way the United States adopts new drug policies, the long-term interests of [patients](#), health systems, insurers, and the government would be better served.

"In July 2015, the Centers for Medicare and Medicaid Services (CMS) announced its plans to reimburse physicians for engaging their patients in advance care planning discussions," Halpern writes. Although he notes that the decision was based on the "valid premise" that communication among all patients and clinicians is an important way to improve the quality of end-of-life care, Halpern says the problem is that "no current policy or practice designed to improve care... is backed by a fraction of the evidence" required for drug approvals in the United States.

Halpern suggests four developments that he calls "attainable," and describes how achieving these goals will help achieve evidenced-based end-of life-care:

- Increased use of large randomized trials and experimental studies that help determine whether current and novel interventions improve outcomes that are important to patients and society. For example, Halpern describes the literature on [advance care planning](#) and completing advance directives as "provocative" but "insufficient" to determine whether these widely advocated practices actually improve patient care and reduce costs.
- Better measures used in studies to quantify the effectiveness of end-of-life interventions. Technological advances that allow for processing of electronic medical record data make it easier to evaluate measures of care that matter to patients and their families. Implementation of these technologies will make it easier to develop large-scale, low-cost assessments of which interventions improve patient and family goals.
- Development of interventions that more accurately show how patients, their families and care teams make decisions about which care plan to pursue. Novel insights into the decision-making process may bring to light options that better serve patients.
- Health systems, insurers, and other entities must be more open to experimentation. Instead of simply being motivated to "do something," opportunities abound for rigorously testing new initiatives, thereby benefiting the long-term interests of both the organizations and the patients they serve. By contrast, Halpern notes that implementing change absent a rigorous evaluation plan crowds out opportunities for learning.

Though encouraged by the enthusiasm of federal organization and their willingness to intervene in [end-of-life care](#) programs, Halpern says the

central challenge today is to "avoid complacency regarding plausibly useful but non-evidence-based initiatives. Researchers, research sponsors, and large insurers, employers and health systems can work together to advance knowledge about what works best for whom."

More information: Scott D. Halpern. Toward Evidence-Based End-of-Life Care, *New England Journal of Medicine* (2015). DOI: 10.1056/NEJMp1509664

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