

# Researchers advocate improvements in end-of-life care

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Three Dana-Farber Cancer Institute researchers, writing in a special issue of *JAMA* published today, make the case for policies and practices that give terminally ill patients more control over how and where they will die.

## Families' views of end-of-life care

An outcomes study led by Alexi Wright, MD, MPH, a researcher and a gynecological oncologist in the Susan F. Smith Center for Women's Cancers at Dana-Farber, surveyed families of older [patients](#) who had died of advanced lung and colorectal cancer, asking what factors were associated with "excellent" end-of-life care for their loved ones.

The families were more likely to assess care as excellent - by relatively large margins - when:

- the patient had [hospice](#) care for more than three days, compared with fewer than three days or none;
- the individual wasn't admitted to an intensive care unit (ICU) in the last 30 days of life;
- the patient died at home or some other location outside the hospital, such as a hospice facility.

"Our study findings are a powerful argument for the importance of [advance care planning](#)," Wright said. "The more information patients

have, the more likely they are to receive the kind of medical care they want near death. And patients' deaths influence family members' perceptions of their quality of care."

Wright reported that end-of-life care could be of higher quality if there are efforts to enroll patients in hospice earlier - not when death is imminent - and to avoid [intensive care unit](#) admissions in the final weeks.

## **Expanding hospice access**

"Barriers to enrolling Medicare patients in hospice are causing those services to be underused," said Oreofe Odejide, MD, MPH, of Dana-Farber/Brigham and Women's Cancer Center.

The Medicare Hospice Benefit created in 1982 enables older adults to receive [hospice care](#), which provides symptom management, home-based care, and support of caregivers.

But some of the provisions of the hospice benefit are hampering wider hospice use, Odejide said in a "Viewpoint" piece in JAMA. Eligibility is restricted to people expected to live six months or less, and the benefit doesn't cover treatment aimed at their underlying disease. Moreover, the fixed daily reimbursement rate makes it challenging for many hospices to provide certain treatments that could improve quality of life for patients in hospice. Odejide said these provisions are a special problem in [end-of-life care](#) for patients with blood cancers such as leukemia, lymphoma, multiple myeloma, and myelodysplastic syndromes. These patients have the lowest rate of hospice use in oncology, and have high rates of intensive care near the end of life.

The suffering and distress of patients with advanced blood cancers can be relieved by measures such as red blood cell and platelet transfusions.

But most hospices don't provide these therapies because of the reimbursement rules.

Change may be in the works. In 2014, Medicare announced a demonstration project under which hospice patients could receive disease-directed care.

"The demonstration project expanded from 30 to 141 hospices, which are beginning services this month. Such policies, if made permanent, could make it easier for physicians to recommend hospice and for patients to choose it," said Odejide.

## **Physician-aided dying**

Terminally ill patients should have the legal option to choose physician-assisted death, even if - as is often the case - they don't use it, wrote Susan Block, MD, founding chair, Department of Psychosocial Oncology and Palliative Care at Dana-Farber and two other authors of a "Viewpoint" opinion piece.

Patients nearing the end of life want control over their bodies and their lives as "a small measure of self-preservation," they noted. Such individuals can gain peace of mind when they have a "back-up" plan, they added.

"When physicians are willing to explore and work with a patient requesting physician-assisted death, patients can experience substantial benefits that are more apparent under an open legal process," said the authors.

Physician-assisted death has been legal for 18 years in Oregon, where only one in 500 [terminally ill patients](#) actually uses it, and providing self-administered medication to accelerate death is legal in five states. To

avoid overemphasizing the role of physicians in such cases, the authors suggest that "hastening death" is a better, less judgmental term.

**More information:** *JAMA*, doi:10.1001/jama.2015.18604

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