

# Perception of US care for the dying worsens

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Surveys of loved ones who lost elderly relatives show that the perception of the quality of care for the dying in the United States has worsened over the last decade. For all the health care industry has done to try to make progress, huge gaps remain between how care is delivered and what patients and their loved ones want, reports a new study in the *Journal of Palliative Medicine*.

"People are less satisfied with care at the close of life, and I think it's now urgent for us to start thinking about what interventions we can do to improve care at the end of life given that we are facing a Silver Tsunami," said Dr. Joan Teno, lead author of the study and professor of health services, policy and practice in the Brown University School of Public Health. The findings come less than a year after an Institute of Medicine report, co-authored by Teno, called for improvements in [end-of-life care](#).

Teno and her co-authors compared data from two surveys—one conducted in 2000 and the National Health and Aging Trends Study done between 2011 and 2013—in which more than 1,200 people who had lost close loved ones in one of those periods rated aspects of the decedents' end-of-life care. In 2000, 56.7 percent of 622 respondents rated care as excellent, but a decade later only 47 percent of 586 people could say the same. Even after the researchers statistically controlled for various possible confounders, including age, race, ethnicity and even the nature of the decedents declining health, the latter sample was still 30 percent less likely to report that care was excellent.

The study concerned people 65 and older who resided in their community, rather than in nursing homes, at the time of death.

While the overall results suggest that care may not be improving for this population, other findings revealed more specific ways in which care either improved or fell short of patient and family desires. For example, a greater percentage of people (25.2 percent in 2011-13 vs. 15.5 percent in 2000) reported an unmet need for pain management, but [health care](#) providers improved in the frequency with which they discussed spiritual or religious concerns with patients and families.

Many quality indicators remained about the same, based on the survey respondents reports. Loved ones, for example, continued to report at about the same rates that decisions were made without enough of their input (13.8 percent in 2011-2013), or against the decedent's preferences (20.2 percent) when the patient was in [intensive care](#) in the last months of life.

The lack of improvement is disappointing, Teno said, because policymakers and health care providers have made many attempts over the last decade to improve end-of-life care.

### **Need for reform**

The most important change has been a vast expansion in the availability of hospice and [palliative care services](#). The new study, and some of Teno's prior work, suggests that while hospice improves care for the dying, it is frequently misapplied.

"It all relates to how we are using it," she said. "One of the concerns is that from a population perspective you may have more people receiving hospice but if they are not receiving enough of those services then it becomes really problematic."

Hospice did elevate the perception of end-of-life care in the new survey. Among a subset of people who lost loved ones between 2011 and 2013, 60.9 percent of those for whom hospice was involved rated care as excellent, compared to 46.7 percent for whom hospice was not involved.

But in the last decade, Teno's work has shown, more people have also been referred to hospice too late to do much good. People have also become more likely to end up in intensive care and to experience burdensome transitions between institutions in the last few days of life.

To a great extent, these trends are driven by how Medicare compensates health [care providers](#). They are paid for performing procedures rather than for assessing the care preferences of patients and their families, wrote Teno and her colleagues in the journal. The private sector may lead the way to change, Teno noted, as providers respond to reforms that steer payments more toward quality and away from raw volume of services.

"Our findings support the 2014 IOM report that calls for improved advance care planning, a major restructuring of our [health](#) financing, increase in transparency, and more accountability of [health care providers](#)," the authors wrote.

Provided by Brown University

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