

Joan Teno, MD: Leader in Crusade for Quality Hospice, Palliative Care

MARY KORR
RIMJ MANAGING EDITOR

PROVIDENCE – The National Hospice and Palliative Care Organization (NHPCO) presented Joan Teno, MD, MS, with its inaugural Quality Leadership Award in April at its annual leadership conference.

In her acceptance speech, Dr. Teno described hospice as the lone voice that proclaimed dying patients and family matter and said that it initially grew outside of mainstream medical care.

“High-quality hospice care is medical care that is competent, coordinated, patient- and family-centered, and delivered with compassion,” she said. “I am honored to accept this



Dr. Joan Teno accepts the National Hospice and Palliative Care Organization's inaugural Quality Leadership Award at the group's 28th management and leadership conference held in April in Bethesda, MD.

award on behalf of the frontline hospice providers who achieve this vision on a daily basis. They are the heart and soul of hospice.”

Dr. Teno is associate director of the Center for Gerontology and Health Care Research at Brown and a professor of health services policy and practice in the School of Public Health. She is also a palliative-care physician at Home & Hospice Care of Rhode Island.

Dr. Teno described the broad scope of her life's work for the *Rhode Island Medical Journal's* special issue on the inaugural School of Public Health at Brown.

Q. What led you to specialize in geriatrics and focus your research on palliative and end-of-life care?

A. Two events greatly shaped my career direction. First, my grandfather died of lung cancer. His physician chose not to tell him that he had lung cancer. This robbed me of the chance to say goodbye. He died while I was flying from Rhode Island to San Francisco.

Second, my initial rotation as an intern at Rhode Island Hospital was in the MICU where Dr. Dan Brock, a medical ethicist, rounded with me. Dan helped me to ask the hard questions about how we were making decisions in these seriously ill patients. He encouraged my interest in specializing in geriatrics and to conduct research in end-of-life care. I feel blessed to be able to have a career that allowed me to follow my passion and hopefully make a difference to improve the quality of dying patients and their family.

Q. Here in Rhode Island, we are aging in place.

How dire is the need in Rhode Island for compassionate end-of-life care as compared to the rest of the country?

A. There are important challenges in Rhode Island. We have one of the shortest hospice median length-of-stay and nearly 40% of dying Medicare beneficiaries are on hospice for 3 days or less. Too often dying patients and family do not get the full benefit of hospice care – only 24 hours of intensive management of pain and other symptoms. This is simply wrong. We as a state should work to ensure that dying patients are informed about their prognosis, treatment options and make sure that they are aware of the important benefits of hospice and palliative care. Being the smallest state in the Union, we could be leaders in improving end-of-life care that is competent, patient- and family-centered, coordinated and compassionate.

Q. Aggressive end-of-life care is not what most patients want. But sometimes there is disagreement within families. How should physicians initiate the discussion with patients and families, who may balk when the physician in the ICU suggests a hospice or palliative-care consultation?

A. First and foremost, bringing up the issue at an early time point is key – don't wait until the patient is actively dying. Hospice is not brink-of-death care, but the full benefits of hospice can't be realized with a length-of-stay of 3 days or less. Prognostication can be difficult. Fortunately, nearly

all hospitals in Rhode Island have physicians and nurse practitioners with expertise in palliative medicine who are there to help physician and other health-care providers with this difficult conversation. So my advice is to utilize those invaluable resources to help seriously-ill patients make choices about their medical care.

Resource for MDs

Dr. Teno recommends the Education in Palliative and End-of-Life (EPEC) website: <http://www.epec.net/>

Recent study in JAMA shows hospice and aggressive care rising

The Feb. 6, 2013 issue of the *Journal of the American Medical Association* includes a study by Dr. Joan Teno and co-researchers on changes in end-of-life care for Medicare beneficiaries, aged 66 and older, who died in 2000, 2005, or 2009.

In the study, patients were classified as having a medical diagnosis of cancer, chronic obstructive pulmonary disease, or dementia in the last 180 days of life. The study cohort included 848,303 fee-for-service Medicare decedents.

Among the findings:

- About 33.5% of Medicare beneficiaries died at home in 2009, 10% more than in 2000.
- 42% died in hospice care in 2009; of these, 28.4% used hospice for 3 days or less.
- Transitions from one care setting to another in the last 90 days of life increased by 50%, from an average of 2 moves in 2000 to 3 in 2009.
- 24% of those who died used the ICU in 2000; the number rose to 29% in 2009.
- Dementia patients spent more time in intensive care in 2009 than in 2000.

In this interview with RIMJ, Dr. Teno stresses the need for physicians and hospitals to focus more on delivering high-quality, patient-centered care that is based on the needs and expectations of an individual approaching the end of life.

Full-study reference:

Joan M. Teno, MD, MS, et al. Change in End-of-Life Care for Medicare Beneficiaries. Site of Death, Place of Care, and Health Care Transitions in 2000, 2005, and 2009. *JAMA*. 2013;309(5):470-477.

Q. If Medicare pays for a skilled nursing facility and not for an extended stay in an in-patient hospice facility, what's a family to do as they seek compassionate end-of-life care for a loved one?

A. The greatest challenge that we face in health care is that we pay for procedures, we pay for another day in ICU, but we don't provide financial incentives that adequately reward high-quality medical care that includes talking with patients about their prognosis and treatment options. For me, high-quality medical care for a seriously-ill person must educate that patient and their family about their prognosis and treatment options, to help them arrive at their goals of care, and then the physician works with a multidisciplinary team to develop a plan of care that honors those goals.

Q. What opportunities will be created by the transition from the program in public health to the School of Public Health at Brown in terms of your research? And in preparing a new generation of palliative-care physicians, academicians and researchers?

A. Brown University has played a very important role in research on the quality of end-of-life care, starting with the National Hospice Study run by former medical school Dean David Greer. At the formulation of hospice in the United States, Dean Greer, Dr. Vince Mor and others played a critical role in evaluating hospice from its onset.

Since that time, my colleagues in the public health program have conducted a number of important studies. Susan Miller has evaluated the role of hospice in the nursing home (NH), producing key research that provides the justification for hospice in the NH. Pedro Gozalo has evaluated the potential cost saving of hospice. Dean Fox Wetle and Renee Shield conducted qualitative research that highlighted the important unmet needs and suffering of dying patients in nursing homes.

I have been very fortunate to partner with the National Hospice and Palliative Care Organization to create the Family Evaluation of Hospice Care Survey that has allowed hospice to audit and improve their quality of care.

And, working with Dr. Mor and Gozalo, we have produced a number of studies that have examined the role of feeding tubes in persons with advanced cognitive impairment – this research has been cited by the American Academy of Hospice and Palliative Medicine (AAHPM) and the American Geriatric Society (AGS). It showed that physicians should offer hand feeding rather than a feeding tube, given the evidence that feeding tubes do not improve survival. And our research found that insertion of a feeding tube during hospitalization may increase the risk of a pressure ulcer by more than twofold.

The School of Public Health will provide an opportunity for Brown to continue in our role of conducting policy-relevant research focusing on the important needs of seriously-ill and dying patients.