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Honoring Final Wishes: How to Respect American's Choices at the End of Life

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Good Morning.

I want to thank you for the chance to speak to you about the needs of older dying Americans. My name is Dr. Joan Teno. I am a Professor of Community Health and Medicine at the Warren Alpert School of Medicine of Brown University. Also, I serve in the role of chair of the Quality & Research Strategic Coordinating Committee of the American Academy of Hospice and Palliative Medicine, the physician specialty society representing more than 3.400 health professionals dedicated to hospice and palliative medicine. For the past two decades, I have had the privilege of conducting research and providing medical care to countless seriously ill and dying persons through my work with Home and Hospice Care of Rhode Island. I have more than 150 publications and numerous grants funded by the National Institute of Aging, the National Cancer Institute and the Robert Wood Johnson Foundation. Yet, if you search my name using Google search engine, the news headline associated with my name is "Cat Predicts Death in Nursing Home." Oscar is a cat that lives in a dementia unit at a RI nursing home that apparently regularly holds death vigils with persons dying from dementia. A short story by my colleague, Dr. David Dosa, that described this process in the New England Journal of Medicine[1] went "transglobal" and led to Oscar's appearances on every major US news network, the BBC, and multiple foreign media outlets. A cat that sits with nursing home residents dying from dementia became the talk of coffee breaks and the dinner tables throughout America. We received countless e-mail messages that spoke of concerns about dying in a nursing home. Indeed, a survey of older persons found the majority of persons would "rather die" than live in a nursing home. Often, person stated in their email messages to us if they could not die at home, they wanted to die at a nursing home with a cat like Oscar. This experience illustrates what a touchstone issue dying in nursing homes are for many people across the country.

Central to improving end of life care in nursing homes is a fundamental first step of promoting patient's choice through advance care planning. Advance care planning is more than just the completion of a written advance directive; rather it is an ongoing communication between a health care provider and a patient that accomplishes two important goals. First, the patient goals and values are clarified often resulting in the completion of a written advance directive. Second, a care plan is created to ensure that the patient's wishes are honored. As I learned early in my medical care while caring for a dying patient just blocks away from the White House, completing and documenting an written advance directive that states that the patient wants to die at home is not enough. As a physician, I must anticipate the problems that may arise in the middle of night and ensure there is adequate medication to provide for that dying patient's comfort. At that time, not many pharmacies were willing to deliver drugs such as morphine in the middle of the night, even just a few blocks away from the White House. Today, I would like to speak with you about the importance of nursing homes in caring for persons at the close of life, the opportunities to improve that care, the evidence that we can improve it, and suggest solutions for the consideration of Congress.

The Evolving Role of Nursing Homes

Nursing homes are the final place of care and site of death for a growing number of Americans. One in four Americans die in a nursing home[2] and nearly 40% were in a nursing home during their last month of life.[3] Nursing homes are the last safety net for impoverished elderly who can't afford the care needed to remain at home. Many don't have families. In high quality nursing homes such as the one that Oscar the cat lives, the nursing home staff – nurses, social workers, physicians, maintenance workers, dieticians, physical therapists and others – can become the sole sources of love and care for these frail, older persons as they die.

The Opportunity to Improve

While most parts of the health care system can improve, the salience of this need for the thousands of frail elderly who die in nursing homes cannot be overstated. In a study we conducted of survivors of individuals who had been in a nursing home in their last weeks of life, we found about one in three people reported the need for better pain control, that they did not have enough emotional support, and stated that their loved one was not treated with dignity. Only 42% rated the care of their loved one as excellent compared to 70% for those persons dying at home with hospice services. [3] Behind these rates lie compelling stories of the urgency and need to improve.

> *As long as somebody was there with [my father], it was fine. And the minute we left, then he was about totally ignored. I went [out] for lunch one day…and came back and they had him in the hall, strapped in a chair, completely slumped over. And, evidently, he had, tried to get out of bed or something and they didn't, they were busy and they didn't feel like they had time to watch him. But he was not properly clothed, and my opinion was at that point they saw him as nothing but an old man. And we had that same experience in the emergency room. And, which was, you know, that was kind of upsetting to see… When the people from the home were there, from the assisted living care facility, when they were there, everything was fine. But the minute somebody was not there in the room with him, then the care very definitely was less acceptable."*
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> *-daughter of a man in his 80s with cancer*[4]

Sadly, too often older persons in nursing homes and their family are "lost in transitions" between an acute care hospital and nursing home. With funding from the National Institute of Aging, (PO1AG027296 and R01 AG024265), I have worked with a multi-disciplinary research team to describe the rate of health care transitions that frail older persons experience and the implications of living in a geographic region with a higher rate of transitions. For frail older persons residing in a nursing home, rates of transitions in the last six months of life vary from a low in 1.9 per person (Salem, OR) to a high of 5.1 transitions per person (Monroe, LA). Such transitions are costly, can often be avoided, and lead to interventions that

many would classify as futile. For example, the literature is unambiguous in documenting that feeding tubes for people with end stage dementia do not improve survival, prevent aspiration pneumonia, or help in healing of pressure sores. Yet persons living in a region with high rates of health care transitions are 2.5 times more likely to have a feeding tube inserted than persons in other regions.

We can improve

One in seven nursing home residents have persistent severe pain.[5] Yet, a study conducted in RI nursing homes and replicated across the nation has demonstrated that we can improve the treatment of pain in the nursing home setting. In a demonstration project done in partnership with the state of Rhode Island, the local quality improvement organization, and Brown University, a multifaceted intervention achieved a 41% reduction in severe pain among residents in participating nursing homes.[6] This effort would not have been possible without the support of the Attorney General's Task Force on End of Life Care created by Senator Whitehouse, then the Attorney General of Rhode Island.

Research clearly shows that hospice improves the quality of pain management, improves satisfaction, and helps to prevent terminal hospitalizations of dying persons. One study that found a 47% reduction in rate of terminal hospitalizations.[7] Hospice teams care for people in their own homes and in special inpatient hospice units. Additionally, a multidisciplinary hospice team provides care for people when their "home" is a nursing home. Hospice is one of the few segments of our health care system that exemplifies patient and family centered care. For those dying in nursing homes, the multidisciplinary hospice team provides hope for a tolerable death not marred by pain or other symptoms, assures emotional support, and treats the older dying American with dignity and respect. Time and time again, I have heard family members state, "I no longer had to fight for the right care. I could just be a daughter grieving for my dying mother." The current efforts to cut $2.2

billion from hospice reimbursement over five years will reduce access to hospice, negatively impact the quality of hospice care, and potentially lead to higher health care costs. A 2007 Duke University study[8] found that hospice saves Medicare an average of $2,300 per patient amounting to a $2 billion per year saving for Medicare. .

There are solutions

First, a key step to decreasing the rate of costly, burdensome health care transitions are efforts to promote advance care planning, including the completion of advance directives. The creation of an advance directive must be clearly linked to a care plan on how a dying persons wishes will be respected.[9-11] Hospice is a crucial element of that care plan. Hospice allows patients wishes to be honored, ensures adequate palliation of symptoms, prevents inappropriate hospitalizations, and provides the appropriate emotional support of the patient and family.

Second, Congress should assure that there are sufficient number of physicians with the needed training and skills in hospice and palliative medicine to meet the growing needs of the aging population.:

- To promote the growth of the new specialty of Hospice and Palliative Medicine, Congress should exempt palliative medicine fellowship slots from the Medicare GME cap on graduate medical education and should treat palliative medicine fellowships as a primary specialty (akin to geriatrics) as opposed to a subspecialty.

- To develop enough faculty to train the next generation, Congress should fund a Palliative Medicine Career Award akin to the successful GACA program established in 1998.

Third, Congress should pass legislation that provides incentives to reduce the number of burdensome health care transitions and instructs CMS to formulate regulations that holds acute care hospitals and nursing homes accountable for poor health care transitions. Gone are the days when a physician should be able to state "out of my hospital, no longer my responsibility." Hospitals and nursing homes must partner together to decrease inappropriate health care transitions in the last months of life. Promoting advance care planning is the key first step. The approach to prevent these costly poor health care transitions will require changes to the financial incentives, public reporting of quality indicators about poor health care transitions, and regulatory scrutiny. For example, the ongoing intervention of Sacramento hospitals working with local nursing homes to promote advance care planning is one such partnership that other regions of the country might consider adopting. The bottom line is that hospitals must be accountable for what happens to older, frail persons when they leave their doors. They must be the leaders in improving the quality of care for their community.

Fourth, the current Center for Medicare and Medicaid Services ruling that will cut hospice reimbursement should be rescinded. I urge support of the Medicare Hospice Protection Act (H.R., 6873 and S 3484). Furthermore, I would recommend expanding the role of hospice in nursing homes. The Medicare Hospice Benefit was designed around the needs of persons dying of cancer. Increasing, dementia is a leading cause of death in the USA. These people need the same access to high quality palliative care in their final stages of life. Among those persons with dementia who are enrolled in Hospice, many are enrolled in the last days of life because of the current perverse incentives to provide skilled rehabilitative services. Congress needs to realign these incentives that keep persons "skilled" while dying in a

nursing home. This current set of incentives contribute to multiple costly, hospitalizations and hospice referral only in the last days of life. This expansion should be done in a manner that guarantees high quality care through appropriate regulatory oversight and public reporting of hospice quality.

So what are the lessons learned from Oscar the nursing home cat who holds vigils with dying persons? Does Rhode Island have a psychic cat? My answer is no—rather we have an exemplary nursing home that partners with Home and Hospice Care of RI to provide high quality care. Oscar is just mimicking the staff's loving care. As one elderly women wrote to us in an e-mail, she hoped that she would die in a nursing home with a cat on her bed. Our hope is that policy makers will recognize the importance of adequate funding so a hospice nurse, social worker, spiritual counselor, and volunteers can be at that patient's bedside. We must adequately fund and demand high quality of care for frail, older Americans whose last home is a nursing home.

I thank you for the opportunity to speak with you today.

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