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Title: Trends in health services use among Medicare decedents

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Good Morning, I want to thank you for the honor of speaking with you today regarding the critical needs of people who are dying and their families here in America. About 2.4 million Americans die each year. Dying is critical event in the life of a family that, without appropriate medical care and support, can result in not only pain and suffering for dying person, but post-traumatic stress and complicated grief for survivors. My charge today is to provide you with the context of dying in America.

Over the past three decades, we have made great progress in the US with the expansion of hospice services and the emerging subspecialty of Hospice and Palliative Medicine. Yet as I will outline for you today, there are important opportunities to improve care for the dying. Our health care system is still a long way from ensuring that medical care at the close of life is based on a patient's fully informed preferences and values.

Changing Demographics and Cause of Death

Successes in public health (e.g., through vaccinations that prevents disease, elimination of small pox) and medical treatments of chronic illnesses have resulted in tremendous increases in longevity. Over the last half century, each year as the Centers for Disease Control releases its new data, we find that the average number of years a 75 year old can expect to live has ticked up a bit. Increasingly, we encounter centenarians. The fastest growing segment of the population are those age 85 and older. Increasingly, this older population is dying of diseases that a century ago were rare; dementia, despite being

unrecognized as a terminal illness, is now the 6th leading cause of death in the USA and one in eight Americans 65 and over are afflicted with Dementia. While these patients have a different dying trajectory than a patient dying with cancer, they have the same needs for their end of life symptoms to be appropriately treated. Pneumonia in a patient with dementia results in the same level of shortness of breath as it does in a cancer patient. Simply stated, dyspnea from a lack of oxygen knows no difference between patients dying of cancer or those dying due to dementia.

Based on our research and that of others, the place of care and geographic region where people live greatly influence how and where they die. In a study we conducted of survivors of individuals who had been in a nursing home in their last weeks of life, found that about one in three reported that their loved one experienced inadequate pain control, that they did not have enough emotional support, and reported that they weren't treated with dignity. Only 42% rated the care their loved one received as excellent. In contrast, among those who died at home with hospice services, nearly 71% rated the care of their love one as excellent and only 3.8% stated that the care their loved one received did not always treat the patient with respect -- nearly 10 times lower than for those who died in a nursing home.¹ Since more and more Americans are spending part of their last weeks of life in a nursing home, this has implications that go far beyond the 1.5 million individuals in a US nursing home on any given day.

Sadly, too often dying persons and their families are "lost in transition" 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 pattern of transitions at the end of life among NH residents with advanced cognitive and functional impairment.² We created an index of burdensome transitions based upon the number of times these individuals moved from one setting to another or changed the teams providing them care. We found that in 2007, nearly one in five NH residents with advanced dementia had a burdensome transition. To illustrate the striking geographic variation we observed, I contrast the pattern of these burdensome transitions in Grand Junction, CO and in McAllen, Texas:

Outcome	Grand Junction, CO	McAllen, TX
Multiple Hospitalizations for Pneumonia, UTI, dehydration in last month of life	0.5%	14.4%
One burdensome transition in last month	12.8%	27.1%
Two or more burdensome transitions in last month	0%	6.2%

High rates of transition from one medical setting to another result in medical errors, problematic care coordination, duplication of services, and relocation stress for these frail older persons. Indeed, the influence of geography and style of care is so pervasive that we

found in areas of the country in which seriously demented nursing home residents had higher than average rates of burdensome transitions, they were more likely to suffer a Stage IV decubitus ulcer in the last month of life, more likely to have an ICU stay, and to experience a late referral to hospice services. Unfortunately, we have little research to help explain why these geographic differences in treatment patterns even for very similar patients, are so stark.

As noted in the *NEJM* article contrasting the health care system of Grand Junction and McAllen,³ the financial incentives of the primary care physicians who run the Rocky Mountain Health Plan have financial incentives that are aligned to promote advance care planning and cost control. However, this area is still a rarity; there are too many areas like McAllen, Texas where transitions are common, uncoordinated, and it is the patients and their families who pay the price.

Indeed, our new research characterizing changes in the site of death, place of care, and health care transitions provides evidence of health care “non-systems” characterized by “more and more” health care utilization at the end of life. While the Centers for Disease Control, using national death certificates, has reported that over the last decade, more elderly persons are dying at home, site of death only tells you where the person was at the moment of death. It does characterize the health care transitions and patterns of medical care in the last months of life.

With funding from the National Institute of Aging, we examined the places of care and health care transitions among Medicare fee for service decedents between 2000 and 2009. We document that indeed more people were dying at home and nursing home and fewer died in hospital in 2009 relative to 2000, we also find an increase in ICU utilization, health care transitions in the last 72 hours of life, and the overall rate of medical setting to setting transitions in the last 90 days of life. Consistent with the “more and more” theme, the use of hospice doubled over the last decade, but 28% of those who used hospice at all, initiated hospice within 3 days of dying in 2009! About one-third of these late referrals were preceded by hospitalization with an ICU stay. Despite the increase in both the availability and use of hospice services, for far too many Medicare beneficiaries, hospice is simply “too late.”

Financial incentives in the current fee for service system are aligned to promote the provision of “more treatments and services” and NOT health care based on informed patient preferences. Honest and complete communication about patients’ and families’ goals of care too often occurs too late. Some attribute this to the presence of perverse financial incentives for more hospitalizations rather than open and frank communications between physicians, patients and families about the goals of care. Where it has happened, aligning the financial incentives and the innovative use of nurse practitioners in nursing home has resulted in fewer hospitalizations, longer survival, and improved quality of care. These are the incentives, combined with accountability, that we want to promote in health care reform so that the right care is delivered at the right time and in the right location.

Based on our own and our colleagues research, we propose the following recommendations for your consideration:

First, it must be clear that a single health care provider, or health care system, is accountable for an episode of care. We should no longer tolerate the sentiment some have expressed: “out of my hospital, no longer my responsibility.” Hospitals and nursing homes must become partners in order to decrease inappropriate health care transitions, particularly in the last months of life. Financial incentives, through bundling of payments or some other mechanism, must be aligned such that a health care system is responsible for an entire episode of care. Without financial and clinical accountability dying patients and their families will continue to be “lost in transition” between the acute care hospital and other health care providers, such as nursing homes, home health, etc.

Second, any changes in financial incentives that shift from incentives to provide “more” care to incentives to provide “less” care under bundled payment arrangements, must be accompanied by oversight to insure that patients and families wishes are honored and that needed care is provided. This could be done using public reporting or random audits informed by data. It important that health care institutions or managed care organizations are held accountable for providing care consistent with a patient preferences and values.

In 2012, Medicare is the predominate payer for an aging population. A fee for service reimbursement system made sense in the early 1960's when the primary concern was to increase access to high quality medical services for the elderly who had generally

been without insurance. However, fee for service payments together with separate reimbursement models for hospitals, doctors, nursing homes and hospices has created health care silos with each type of provider concerned only what goes on within the walls of their system. We believe that it is essential to move the current system toward increased accountability, whether with managed care or accountable health care systems embracing all types of providers. Otherwise, I worry that frail elderly individuals will be transferred from one provider to another like so much flotsam and jetsam.

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

References.

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