

Hospice and Palliative Care

An Essential Component of the Aging Services Network

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I appreciate the opportunity to speak before you today. My name is Dr. Howard Tuch. I am a Hospice and Palliative Medicine physician and geriatrician in practice at Suncoast Hospice in Pinellas County, Florida. I am here representing the American Academy of Hospice and Palliative Medicine, a rapidly growing medical specialty organization with nearly 4000 members. The re-authorization of the Older Americans Act is an opportunity to address existing gaps in health care and social services that older people face in the last years of their lives. Palliative care has much to offer elders and communities and should be formally integrated into the aging services network.

Palliative Care is health care focused on relief of suffering and support for best possible quality of life for people facing serious and advanced illness.

It has three domains:

- Relief of pain and other distressing physical and emotional symptoms common in advanced illness. Unlike hospice, palliative care is not prognosis driven. Patients do not have to be close to death to have access to, or benefit from palliative care services.
- Attention to transitions and continuity of care across health care sites. 20% of Medicare beneficiaries are re-admitted to hospitals within 30 days of discharge. Many discharges are avoidable and most are enormously burdensome and costly to both patients and the health care system.
- Communication and relationship building. Taking the time to truly engage in shared-decision making and care planning with patients and families is crucial to ensuring that care is concordant with patient wishes.

The distinction between formal hospice care and palliative care is an important one to make. Hospice offers comprehensive and ongoing interdisciplinary care for patients, and families, at the end-of-life. To be eligible for hospice, patients must have a life expectancy of 6 months or less and importantly, must choose to forgo efforts at curative treatment for their terminal illness. Hospice care is most often provided in a patient's home and the majority is funded through the part A Medicare hospice benefit, although most insurance programs have similar benefits.

Hospice is truly end-of-life care and has an essential role in health care. The median length of service on hospice is about 20 days and nearly a third of all patients admitted to hospice care die within 10 days of admission. The growth of hospice has been dramatic in recent years: about 10% per year and this past year nearly 1.4 million patients (40 % of all Medicare decedents) were admitted to hospice care¹. While it may surprise some, about 60% of patients currently admitted to hospice do not have cancer diagnoses: hospice patients are increasingly likely to be elderly with multiple illnesses, frailty and the end-stages of heart disease and lung diseases and dementia². Predicting how long these patients are likely to survive, a required condition of admission to hospice is very difficult. There are few clear boundaries or reliable clinical indicators marking entry to the "end-of-life". For many patients, perhaps the majority of dying patients, end-stage means years, not weeks or months, of living with severe and disabling illness. This uncertainty and the need to forgo curative treatment may be responsible for the many late referrals to hospice. Aging and health care services will need to be designed with this time frame in mind. Frailty is common in the last years of life and aggressive medical intervention can be quite burdensome. It is here that palliative care can be most useful and most successfully integrated in community-based aging services.

¹ MedPAC March 2009 Report to Congress, Chapter 6 Reforming Medicare's hospice benefit

² NHPCO Facts and Figures: Hospice Care in America, Oct 2008

Palliative Care (PC) has grown rapidly in the last decade. Over 50% of hospitals in the country with more than 50 beds have a palliative care service, either in the form of a consultation team or inpatient unit³. Palliative care is usually offered through an interdisciplinary team consultation, billed through Medicare part B and, until now, has mostly been available to hospitalized patients. A growing evidence base has demonstrated the potential of PC to control costs, improve quality and enhance patient and family satisfaction for a rapidly expanding population of patients with multiple chronic conditions and life-threatening illness⁴. Interdisciplinary palliative care teams manage pain and other distressing symptoms; actually talk to patients and families (and their doctors) to establish clear and achievable treatment goals, including withdrawing or avoiding interventions that do not meet their goals. They develop transition plans for complex patients. A recent cost study involving 8 US hospitals and thousands of patients's demonstrated savings of nearly \$1700 for patients discharged and nearly \$5000 per patient dying in the hospital. The savings following PC consultation were derived from patient and family decisions resulting in fewer ICU days, medications and diagnostic procedures. The rapid diffusion of PC services reflects both the benefits that patient and families experience and the strong case that these services reduce the costs of managing complex patients. Palliative care programs are increasingly available in community and long-term care settings as well.

I want to provide an example of the kinds of problems that I encounter commonly in my practice. I work with a hospice and palliative care team of nurses, social workers, aids and a chaplain, which cares for patients mostly living in nursing homes and assisted living centers. Our patients are elderly, with multiple medical and functional problems including cancers, end-stages of dementia, heart disease, diabetes and vascular disease. Most are cognitively impaired and need help with their daily personal needs. Families often do not live close by and our staff and that of the nursing home become surrogate family members.

One patient's story was as follows:

Mr. M was an 83 yo patient who had been living in a nursing home for over a year. He was "dually eligible", covered by both Medicare and Medicaid and suffered from multiple chronic illnesses including severe lung disease, dementia and vascular disease. He had difficulty swallowing and had been admitted to a hospital twice with pneumonia over the

³ Center to Advance Palliative Care (CAPC) (<http://www.capc.org>)

⁴ Morrison RS, Penrod JD, Cassel JB, Caust-Ellenbogen M, Litke A, Spragens L, Meier DE. Cost savings associated with US hospital palliative care consultation programs. Arch Intern Med 2008;168:1783-90

previous 6 months. He had not completed an advance directive and deferred to his family for decisions. Each hospital stay resulted in further loss of function, weight loss and declining strength. Just prior to our involvement, he was admitted for a third time to the hospital, again with a diagnosis of pneumonia. His stay was complicated by acute confusion, anemia, more weight loss and now appeared to be in significant pain. Placement of a feeding tube to meet his nutritional needs was offered but declined by family. The family refused to consider a hospice referral. He underwent multiple diagnostic procedures and scans, and after 6 days returned to the nursing home (NH) on several new medications. Although he was seen in the hospital and considered for hospice admission, he returned to the NH for a "skilled" part A Medicare reimbursed stay. In the SNF, IV medication was continued and skilled rehab was offered for 18 days when it was determined that Mr. M could no longer participate due to his weakness and confusion. He was then referred to our palliative care team for evaluation.

His family was supportive, believed that he had not benefited from recent hospitalizations but felt that they had no choice but to return him to the hospital when he became acutely ill. Mostly they did not want him to suffer any longer. The team evaluated the patient, developed a supportive care plan, and managed his pain and severe shortness of breath. We had extensive dialogue with family who, after seeing the potential for support in the nursing home, decided that they no longer wanted him to return to the hospital. He died peacefully in the NH with family and staff present 2 months later.

In the last months of Mr. M's life, he had an extensive tour of our health care system. From NH to hospital to skilled rehab back to hospital, back to skilled rehab. I can't tell you if any of that care prolonged his life. I can tell you that many of the management decisions were born out of poor communication, no planning, inadequate management of symptoms and conflicting incentives driving care. Earlier hospice involvement or PC consultation during any one of three hospitalizations may have altered his trajectory of care, spared Mr. M and family much suffering and saved the health care system and the family tens of thousands of dollars. This is a story that is all too common.

Many of the problems of our current system: uneven quality, over-utilization, lack of coordination and preventable transitions between health care institutions become particularly evident in the last years of life⁵. Chronically and seriously ill patients constitute only 5-10% of patients, account for over 50% of health care costs and over 25% of Medicare costs are incurred in the last year of life. Improving care in the last stages of life will be necessary to create a sustainable health care system.

⁵.Tracking the Care of patients with Sever Chronic Illness, The Dartmouth Health Atlas 2008, http://www.dartmouthatlas.org/atlas/2008_Chronic_Care_Atlas.pdf

Many have defined good quality of care as that which offers the “right care for the right patient at the right time.” For far too many Americans obtaining good care in the last stages of life is more a matter of luck. You have to be lucky that your primary care physician (if you have one) has spoken to you about an advance care plan, that your oncologist will be as skilled in pain and symptom management as administering chemotherapy or that the doctors and nurses in the ER will be able and willing to treat your pain. Lucky that the hospital staff will help you evaluate your options for care and have sufficient staff to attend to help your family through the maze of our current health care system.

As I get older I don’t want to have to be lucky to get good care. I want a default system of good care. Everyone should have access to high quality hospice and palliative care and an expectation of good pain and symptom management. We should all expect open and honest communication about treatment options and truly informed and shared decision making.

Perhaps our biggest challenge is the need to recognize the time frame involved in “end-of-life care”. The trajectory of dying has changed over the past century with the success of medicine and other public health measures. We use to “get sick and die”, all described in one sentence and occurring over a very brief period of time. Most of us will not end our days like this. We will spend years living with the chronic illnesses that will eventually claim us. It is entirely possible to live well with those illnesses and to have a health system and a network of aging services that plans accordingly. The good news is that we have evidence-based models of hospice and palliative care that have been shown to improve care and quality of life for frail elders. The aging services network, with its growing attention to care management, home and community-based services and caregiver support should embrace these models.