

Statement by

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Chairman Pitts, Ranking Member Green and Members of the Energy and Commerce Committee Health Subcommittee. Good morning and thank you for the opportunity to address the Subcommittee. My name is Sean Morrison and I am a physician, Professor and Vice-Chair of Geriatrics and Palliative Medicine, and Director of the Hertzberg Palliative Care Institute at the Icahn School of Medicine at Mount Sinai. I also direct the National Palliative Care Research Center in New York City – a philanthropically funded organization dedicated to improving the evidence base for the care of persons living with serious illness and their families. I am a former President of the American Academy of Hospice and Palliative Medicine and am here today representing the Patient Quality of Life Coalition; a group of over 40 patient, provider and health system organizations including the Academy. The Patient Quality of Life Coalition was established in 2013 and is focused on improving quality of life for patients with serious illness and their families. Thank you for the opportunity to testify before the Subcommittee in support of H.R. 3119, the Palliative Care and Hospice Education

and Training Act. I'd also like to thank Representative Engel, particularly, for his leadership and sponsorship of this important legislation, as well as note the strong bipartisan support the legislation has from over half of the full committee Membership of the Energy and Commerce Committee signed on as co-sponsors.

Palliative care is a relatively new medical and team-based specialty devoted to improving the quality of life – through expert pain and symptom management; skilled communication about what matters most to patients and their families; and well-coordinated and communicated care over the course of a serious illness. Palliative care is delivered at the same time as curative or disease-directed treatments and eligibility is based on patient need and not on prognosis. H.R. 3119 would address three important public policy issues that have been identified as necessary to provide patients with serious illness better access to palliative care services throughout the continuum of their care: Public and Professional Education, Workforce Development, and Research.

Since completing my training in 1995, my research, clinical care, and teaching activities have focused exclusively on improving quality of life for persons living with serious illness and their families. With my colleague Dr. Diane Meier, I established one of the first five palliative care programs at an academic medical center. I have served on national committees that have focused on enhancing research and clinical care for the seriously ill for the National Institutes of Health, Institute of Medicine, and National Quality Forum. I have been continuously funded by the National Institutes of Health for the past 20 years and my research has focused exclusively on improving care for persons

with serious illness and their families. I am an active clinician caring for seriously ill patients and families in both inpatient and outpatient settings.

The elimination of suffering and the cure of disease are the fundamental goals of medicine.¹ Although medical advances have transformed previously fatal conditions such as cancer and heart disease into illnesses that people can live with for many years, they have not been accompanied by corresponding improvements in the quality of life for these patients and their families.² Living with a serious illness should not mean living in pain or experiencing symptoms like shortness of breath, nausea, or fatigue. Yet, multiple studies over the past two decades suggest that medical care for patients with advanced illness is characterized by inadequately treated pain and other physical distress; fragmented care systems; poor communication between doctors, patients, and families; enormous strains on family caregiver and support systems and escalating health care resource use.² Five percent of Medicare enrollees account for over 50% of Medicare spending and, contrary to popular perception, only 11% of these persons are in the last year of life.³ The majority of high cost beneficiaries live for multiple years with progressively debilitating illness.³ Over the next decades most health care professionals will be caring for seriously ill older adults and their families with multiple chronic conditions, multi-year illnesses, and intermittent crises interspersed with periods of relative stability.^{4,5}

What is Palliative Care and Why Is It Needed?

Palliative care is interdisciplinary team based medical care focused on relief of pain and other symptoms and support for the best possible quality of life for patients

with serious illness and their families. Palliative care should be initiated starting at point of diagnosis of a serious illness and is provided alongside all other appropriate medical therapies including those directed at life prolongation and cure throughout the entire course of illness.⁵ Palliative care programs have been shown to reduce symptoms and enhance quality of life, improve doctor-patient-family, satisfaction with care, enhance the efficiency and effectiveness of hospital services, reduce healthcare costs, and in cancer patients, improve survival.^{2,6-8} Over 95% of all mid-large size hospitals in the United States now have palliative care teams and models of palliative care delivery are being rapidly created and disseminated in non-hospital care settings.⁹ This growth is in response to the increasing numbers and needs of Americans living with serious, complex, and chronic illnesses, and the realities of the care responsibilities faced by their families.

The development of the specialty of palliative care has been a critical step in addressing the unmet needs of patients with serious illness and their families and the growth of this field has been remarkable. Nevertheless, challenges remain if care for seriously ill patients and their families is to improve in the United States. Most patients and families who could benefit from palliative care do not know of its existence or equate palliative care with end-of-life care or hospice and thus cannot or do not request palliative care when they can most benefit from it: early and throughout the course of a serious illness¹⁰ Because of lack of investment, and unlike other areas of healthcare, the knowledge base to support the core elements of palliative care clinical practice (i.e., pain and symptom management, communication skills, spiritual support, practical

support for patients and family caregivers, care coordination) is inadequate and care models developed to support the needs of patients and families have yet to be evaluated.² That is, the evidence base to assure high quality clinical care and guide appropriate institutional and system benchmarks is lacking. Finally, although progress has been made in hospitals such that 95% of mid-large size hospitals have palliative care teams and two thirds of all hospitals now provide palliative care, many of these programs are understaffed and only able to care for a fraction of eligible patients.⁹ Furthermore, the majority of nursing homes and community healthcare settings outside of hospitals lack integrated and adequately supported palliative care programs.

Ensuring Access to High Quality Palliative Care

A number of key initiatives need to be undertaken for palliative care to be accessible to all patients with serious illness. First, there need to be patient and provider educational initiatives to increase awareness of the benefits of this care, in the setting of a serious illness and the difference between palliative care and end-of-life care or hospice. Second, there need to be work force initiatives to ensure sufficient numbers of palliative care specialists to teach healthcare trainees and practicing clinicians in the core knowledge and skills of palliative care, conduct the needed research to enhance the evidence base, and provide appropriate care for the most complex population of those with serious illness and their families. Similarly, non-palliative care specialists need to learn core palliative care knowledge and skills given that there will never be enough specialists to provide this type of care. Third, research initiatives are necessary to augment the current inadequate evidence base. H.R. 3119,

the Palliative Care Hospice Education and Training Act would address all three of these important policy changes, and allow for greater patient access to palliative care services for patients and their families.

Public and professional misperceptions

A major issue impeding access to palliative care is the perceptions among doctors and other healthcare professionals that palliative care is appropriate only at the end of life, that palliative care is synonymous with hospice, and that patients will react negatively and lose all hope if palliative care referral is discussed.^{11,12} This is perhaps not surprising given that clinicians, particularly those trained more than 10 years ago, received little to no training in the core knowledge and skills of palliative care nor were they exposed to modern palliative care teams during their educational training. While many physicians have misperceptions about palliative care, most patients do not know anything about it. A recent survey showed that almost 90% of adults in the United States had either no knowledge or limited knowledge of palliative care. However, when read a definition for palliative care, more than 90% of the respondents stated that they would want palliative care for themselves or their family member and that it should be universally available.¹⁰ Targeted social marketing and educational efforts must be directed both to the public and to medical professionals. A national educational campaign to increase public and professional awareness about palliative care and its quality of life, family, and survival benefits, as called for in H.R. 3119, is critically needed. Such a campaign would define palliative care as appropriate care for persons with any serious illness throughout the course of their disease, encourage patients and families

to seek high quality palliative care early in the course of illness, and educate healthcare professionals as to the appropriate role of palliative care in the care of their patients.

Workforce Initiatives

Workforce shortages also prevent many patients from accessing or using palliative care services. The number of palliative care specialists falls far short of what is necessary to serve the current population in need despite the fact that the American Academy of Hospice and Palliative Medicine and the Hospice and Palliative Nurses Association are among the fastest growing professional membership organizations in medicine and nursing respectively. A 2010 study estimated that over 12,000 full time palliative care physicians were needed at that time just to meet current demand for palliative care services in the United States.¹³ The demand for palliative care professionals in 2016 is even greater. Similar shortages exist across the other core palliative care disciplines of nursing, social work, and chaplaincy. The demand for the expansion of palliative care services in community care settings that was created by incentives under the Affordable Care Act, the Joint Commission Advanced Certification for Palliative Care, and the increasing palliative care infrastructure in both public and private sectors of healthcare is further straining the limited specialist-level palliative care workforce.

A major reason for this shortage is the “newness of the field”. Palliative medicine was recognized as a subspecialty by the American Board of Medical Specialties only in 2008. In 2016, only 119 fellowship programs accredited by Accreditation Council for Graduate Medical Education and 15 fellowship programs accredited by the American

Osteopathic Association existed in this country, together graduating a total of 296 new palliative care physicians each year (personal communication, Steven Smith, American Academy of Hospice and Palliative Medicine). Furthermore, because the Balanced Budget Act of 1997 placed a limit on the number of Medicare-supported residency slots before palliative medicine was formally recognized as a medical subspecialty by the American Board of Medical Specialties, specialty training in palliative medicine is entirely dependent on private sector philanthropy or variable and inconsistent institutional support and not by Medicare funding, as is the case with all other medical training in this country. Palliative care specialists are critically needed to teach and mentor healthcare trainees and practicing clinicians in the core knowledge and skills of palliative care, conduct the needed research to enhance the evidence base in order to provide the highest quality care to patients with serious illness and their families, and provide appropriate care for the sickest and most complex population of those with serious illness and their families.

Creating a specialist workforce is not enough, however, to ensure that patients with serious illness and their families receive the care that they deserve. As noted above, the specialist workforce will never be large enough to meet the needs of those Americans with serious illness and their families. Enhancing the palliative care knowledge and skills of ALL front-line clinicians must occur if care for the seriously ill is to improve. Expanding core palliative care knowledge and skills of all clinicians will be a key step toward resolving the shortage in the palliative care specialist workforce. The core palliative care competencies of skilled communication, expert pain and symptom

management, and psychosocial assessment remain, at best, a small part of most medical school and residency training programs. The vast majority of practicing physicians and trainees have either rudimentary or no skills in these areas, which negatively affects patient and family outcomes. Indeed, after 10 years of graduate and post-graduate medical education from 1986-1996 at the University of Chicago, the New York Hospital Cornell Medical Center, and the Mount Sinai School of Medicine, I had received only a thirty-minute lecture on pain management – it occurred in my first year pharmacology course and focused on how opioids bind to nerve cells, are metabolized in the liver, and excreted in the kidney. How to approach and treat the patient in pain or how to effectively communicate to patients a serious diagnosis, discuss goals of care, address prognosis, or facilitate complicated decision making in the setting of serious illness was never covered during my education. From research conducted over the past ten years, we now have a body of evidence that demonstrates that these skills (particularly communication skills) can be effectively learned and developed and are associated with improved outcomes.¹⁴⁻¹⁶ Strategies to expand training in core palliative care knowledge and skills to all clinicians – those in training and those already in practice are needed. H.R. 3119 would establish an education and training program modeled after the successful geriatric education and training programs created a number of years ago, that allow for support of palliative care curriculum development in medical schools and training programs in palliative care for all key healthcare professionals required to provide palliative care – doctors, nurses, social workers and certified healthcare chaplains.

Knowledge and Evidence Base

Reports from the Institute of Medicine in 1997, 2001, 2003, 2015^{4,17-19} have consistently called for major federal investments in palliative care research and yet to date, these calls have remained unanswered. Unlike other areas of medical research traditionally funded by the NIH, the knowledge and evidence base to support core elements of palliative care clinical practice (i.e., pain and symptom management, communication skills, care coordination) is inadequate. The reasons for this distressing state of affairs are many, but almost all stem from a philosophy of medical research that has traditionally viewed symptoms and suffering as unimportant in themselves and interesting only insofar as they guide the physician to a correct diagnosis.²⁰ The prevailing philosophy dictates that once the diagnosis is made (e.g., cancer) and the disease is treated (e.g., chemotherapy), the symptoms (e.g., breathlessness, pain) will dissipate. What is left unsaid is what happens when the disease can't be cured, or is only partially treated or managed, or the treatment itself results in temporary or permanent distress and disability.²⁰ It is not surprising, perhaps, that a comprehensive review of research in palliative medicine supported by the National Institutes of Health (NIH) revealed the data that should guide the treatment of human suffering associated with serious illness of all kinds are not only inadequate but in many instances are completely absent. As a result, current clinical practice regarding symptoms is driven not by evidence but by extrapolation from other situations, small and underpowered or single site studies, and is often anecdotal or based on hearsay and therefore not based on valid science.²⁰

Key research needs to be funded and performed if palliative care is going to achieve its potential to enhance value throughout the health care system. First, important gaps in clinical evidence need to be addressed so that persons with serious illness can receive the best available care. For example, because the mechanisms underlying symptoms are poorly understood, treatments for symptoms such as breathlessness, fatigue, itching, delirium, anxiety, and even pain are primitive compared the science underlying many disease treatments. Indeed, it is almost beyond comprehension that the most effective treatment for severe pain in the setting of most serious illnesses remains opioids with all of their attendant complications and risks – a fact that has not changed since the 1600s. Treatment for nerve (neuropathic) pain, a common complication of diabetes and cancer, is even less effective. Fewer than 2/3rds of patients with severe neuropathy have responses to the best available treatment and only 20% of these patients report fifty percent improvement in pain relief.²¹ Although a recent report points to the success of non-pharmacologic measures in the treatment of chronic pain (such as low back pain or migraines), none of these treatments act immediately and most are ineffective for the most severe pain syndromes associated with a serious illness like cancer. It is hard to imagine that we would tolerate this state of affairs if we were considering conditions of high blood pressure or diabetes or cholesterol, rather than pain and other sources of human suffering.

Second, the needs of older adults with serious illness and their caregivers and the long term and changing nature of those needs are not well described. In particular, the complex care needs of patients with multiple coexisting conditions and functional

dependency must be investigated. The ability to identify and support the population at risk requires moving beyond prognosis and diagnoses to include powerful predictive factors such as needing another person to get through the day, and prior need for institutional care.²²

Third, data to guide care for seriously ill children are needed. Although the numbers of children living with serious illness are notably smaller than those of adults, in 2010, 45,000 children died in the United States, over 25,000 thousand children are living with a serious illness at any given time, and nearly 17 million adults are serving as caregivers to a seriously ill child.^{19,23,24} Despite the need, the evidence on how best to deliver palliative care for seriously ill children is almost non-existent. Finally, the development and evaluation of palliative care–delivery models outside hospitals (in people’s homes, nursing homes, office practices) is essential. To achieve this goal research funding for palliative care will need to be increased beyond the 0.01% of the National Institutes of Health budget that currently supports research on palliative care.²⁵ H.R. 3119 would require the director of the National Institutes of Health to expand and intensify research on palliative care, and pain and symptom management across institutes at the NIH.

Conclusion

Research has conclusively demonstrated that most seriously ill Americans experience treatable suffering and many are impoverished because of uncompensated medical care.²⁶ At the same time, rising government healthcare expenditures threaten to bankrupt Medicare.²⁷ Palliative care offers a rational solution to this problem by

improving quality of life and quality of care and in so doing substantially reducing need for costly crisis care for the highest risk and highest need patient population. The evolution and growth of palliative care in the United States has resulted from the combined investments of both the public and the private sectors. Substantial private-sector contributions exceeding \$300 million in the last twenty-five years²⁸ have created the new field of palliative care and are reflected in the growth of hospital palliative care services, education and training for health professionals, and formal recognition of subspecialty status for physicians and nurses. Commercial and integrated health plans are experimenting with creative benefit design supporting palliative care delivery resulting in better value.²⁹⁻³² The combined and sustained commitment of both the private and the public sectors will be necessary to bring the palliative care innovation to scale in the United States. As Hubert H. Humphrey said at the dedication of the Humphrey Building in 1977 “the moral test of government is how that government treats those who are in the dawn of life, the children; those who are in the twilight of life, the elderly; and those who are in the shadows of life; the sick, the needy and the handicapped.”³³ The provisions in the bill under consideration, H.R. 3119, the Palliative Care and Hospice Education and Training Act will contribute significantly to addressing the barriers preventing all Americans from enjoying the highest quality of life in the setting of serious illness. In closing, I’d like to express again my thanks to Chairman Pitts and Ranking Member Green, as well as to all of you on the sub-committee for allowing me to address this issue with you today.

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