STATEMENT OF THE
NATIONAL COALITION FOR HOSPICE AND PALLIATIVE CARE
TO THE
INSTITUTE OF MEDICINE (IOM) IN SUPPORT OF RECOMMENDATIONS IN
DYING IN AMERICA: IMPROVING QUALITY AND HONORING PREFERENCES
NEAR THE END OF LIFE

MARCH 20, 2015

The National Coalition for Hospice and Palliative Care welcomes the opportunity to support the recommendations contained in the IOM Report: Dying in America: Improving Quality and Honoring Preferences Near the End of Life, published on September 17, 2014. The eight national organizations that comprise the Coalition represent the spectrum of specialties and disciplines engaged in enhancing care for people with serious illness and their family caregivers, including, but not limited to, hospice and palliative care providers (chaplains, nurses, physicians, and social workers) as well as palliative care programs and researchers.

The Coalition commends the IOM for tackling this critically important issue which impacts, or will impact each and every person in our society; how can one’s individual goals of care near the end of life be honored? The research and data presented in this seminal report indicate that for millions of Americans needs near the end of life are not being met. The IOM Report recommends transformative changes related to societal views of mortality as well as specific recommendations regarding increasing and improving access to both palliative care and hospice.

The Coalition strongly supports the overarching recommendation that “high quality compassionate, cost effective, person and family centered care should be accessible to anyone with a serious, advanced illness or near the end of life”. (IOM, 2-45) The Coalition is committed to working across disciplines, with external organizations, key opinion leaders and health care policy makers on numerous policy proposals to turn this recommendation into a reality for millions of patients and families.

Our Coalition is interdisciplinary in nature and works inter-professionally with chaplaincy, medicine, nursing and social work and can effectively work across an even wider set of disciplines to promote and publicize the key recommendations in the IOM Report. The Coalition believes that the message that “early provision of specialty palliative care improves quality of life, lowers spending and helps clarify treatment preferences and goals of care” will resonate with key health care decision makers and key opinion leaders. (IOM 2-24, Parikh et al 2013). Our Coalition Members have reached out to other health care providers and patient advocacy organizations that serve critically ill patients to encourage the wider dissemination of the IOM Report and encourage action on the recommendations. The Coalition also intends to utilize the
evidence presented in the IOM Report in our discussions with key policy makers within Congress, the Centers for Medicaid and Medicare Services, the National Institutes of Health (NIH), the Agency for Healthcare Research and Quality (AHRQ) and the Patient Centered Outcomes Research Institute (PCORI).

The Coalition, and our Members, are committed to using the IOM Report as the basis and rationale for numerous public policy positions and to make the case that it is a national imperative to increase access to palliative care and hospice for everyone experiencing a serious advanced illness.

Key messages from the IOM Report are not well known within the wider medical, nursing, social work and chaplaincy field, let alone within the patient community or with the public. The IOM Report (2-44) clearly presents the evidence that the “Impact of hospice and palliative care on longevity” is a positive one and that earlier access to palliative care and hospice significantly improves quality of life. This is demonstrated by numerous research studies cited by the IOM Report which also confirm that patients and families want; “information and communication about hospice and palliative care, access to home care, emotional and spiritual support, well-being and dignity, care at time of death and a lighter symptom burden”. (Casarett et al 2008)

The Coalition supports the recommendations contained in the IOM Report about the need for earlier referral to hospice due to the multiple, well designed, rigorous peer reviewed studies that demonstrate that quality of care in hospice far exceeds that in traditional care for seriously ill patients near the end of life. In fact, 9 out of 10 adults would prefer to be cared for at home rather than in a hospital or nursing home if diagnosed with a terminal illness. As the IOM Report states, and multiple consistent studies demonstrate, quality end-of-life care reduces unnecessary hospital costs by reducing readmissions, emergency department visits and intensive care stays.

The Coalition pledges to work on policy proposals which will lead to increased access to palliative care earlier in the disease process as well as earlier referral to hospice so that everyone has the highest quality of life for the longest time possible.

Recommendation #1 Delivery of Person Centered, Family Oriented End of Life Care

Proposed Core Components of Quality End of Life Care: The Coalition strongly supports and is committed to the Proposed Core Components of Quality End of Life Care as these are based on the National Consensus Project for Quality Palliative Care, which is an initiative of the Coalition. These proposed core components serve as a roadmap for professional organizations and health care institutions as they work to achieve each of these components to ensure that anyone diagnosed with a serious illness regardless of age, location, or prognosis has access to quality palliative care. Our Coalition is fully committed to the interdisciplinary nature of the hospice and palliative care team and will communicate to healthcare policy makers (including insurance companies, health care institutions and CMS) the importance and necessity of having physicians, social workers, nurses and chaplains available to address the complex challenges faced by patients and families living with serious illness.

- As the field of palliative medicine and nursing is relatively new, one of the most critical recommendations is to communicate with other health care professionals, administrators and institutions about the benefits of palliative care. There is strong evidence that palliative care can reduce unnecessary hospital admissions and re-admissions which are not only costly and risky for vulnerable patient populations but cause distress, pain,
and emotional turmoil in patients and their families. A growing body of evidence suggests that the risks of hospitalization in terms of hospital acquired infections and other hazards is a significant contributor to increased and earlier mortality. Avoidance of unnecessary hospitalization achieves the triple aim of better quality, better care, and lower costs.

- The IOM Report states that “transparency and accountability through public reporting of aggregate quality and cost measures for all aspects of the health care system related to end of life care” is needed. (IOM Report 2-45). Coalition Members are committed to supporting the development, testing and validation of quality measure in this arena. An important initiative of two of the Coalition Members, the American Academy of Hospice and Palliative Medicine and the Hospice and Palliative Nurses Association have created an interdisciplinary approach, Measuring What Matters, to sort through all relevant published measures and select a concise measure-set of outcomes that would matter most for patients with palliative care needs across all settings. Voluntary adoption of these measures broadly in hospice and palliative care would lay the groundwork for benchmarking and meaningful comparison. The Coalition supports the continuation of this project and the potential for CMS to include appropriate measures in future Medicare programs once they have been appropriately benchmarked, tested and validated.

- The IOM Report makes the case that millions of Medicare beneficiaries experience unnecessary and overly burdensome transitions that have led to very high rates of preventable hospitalizations. The Coalition pledges to work with external organizations, government agencies, and other coalitions to address meaningful payment reform to reduce these high rates of burdensome health care transitions.

Recommendation # 2: Clinician-Patient Communication and Advance Care Planning (ACP)

The Coalition strongly supports the recommendations contained in the IOM Report regarding the need to strengthen both the quality and the quantity of clinician-patient communication. Advance care planning conversations and appropriate ACP document completion is one aspect of this communication which also needs to be increased and enhanced. Conversations which lead to shared decision-making “is an essential component of quality care”. (IOM 3-38) The Coalition will advocate for ACP that is focused on on-going high quality conversations between the health care team and the patient and family about values and preferences and not on document completion alone.

- The quality of these conversations cannot be overlooked in favor of a check-list-type documentation that these conversations have or have not occurred. The Coalition supports government and private payer reimbursement for the interdisciplinary team to initiate and conduct these crucial conversations and has communicated its support to CMS for their proposal to reimburse qualified health care providers for these conversations. The Coalition will continue to advocate for public policy proposals that acknowledge the time, expertise, and skill necessary to have these conversations. The aim of these conversations is “to develop a coherent care plan that meets the patients goals, values and preferences” (IOM Report: Walling et al 2008 3-3)
• **Advance Care Planning (ACP):** ACP is one component of the ongoing conversations about patient and family goals, values and preferences. The Coalition is committed to raising awareness of the importance of ACP throughout one’s life, not just at the end of life, as recommended by the IOM. The Coalition has recently joined others to promote National Health Care Decisions Day and plans to partner with other organizations dedicated to raising public awareness of the public and professional responsibility to have these crucial conversations.

• **Electronic Health Record:** The Coalition is supportive of changing the electronic health record (EHR) to safely and securely document a patient’s advance care plans and preferences for goals and settings of care, and is interested in exploring and partnering with other organizations in our field and the wider health IT field to determine how best to approach this technical problem. (IOM Report, 3-52) The Coalition is considering recommendations regarding the implementation of the Health Information for Economic and Clinical Health (HITECH) Act whereby physicians and hospitals need to demonstrate “meaningful use” of electronic health records. Historically, advance care planning documentation and data standards are minimal. However, there is great potential to promote a standardized approach to appropriate advance care planning through the EHR. The Coalition supports efforts to make advance care planning a meaningful and universal component in the EHR.

• The Coalition supports the documentation measures as described in the NQF National Framework and Preferred Practices for Palliative and Hospice Care Quality and will work with other stakeholders to implement and expand this Framework. (IOM Report 3-42)

• The Coalition is concerned that standards for quality conversations and widespread training for all clinicians who take care of seriously ill patients are lacking. The Coalition is interested in working with key stakeholders to create standards in this arena.

Good communication skills are like any other complex procedure needed for quality patient care. Improving the communication skills of health care providers requires additional training, guidelines and appropriate documentation, as would be required for example after a complex surgical procedure. The Coalition is committed to enhancing these efforts.

**Recommendation # 3 Professional Education and Development**

The Coalition strongly supports the recommendations for universal health professional education in the core principles and practices of palliative care and recognizes that as hospice and palliative care specialists our organizations must partner and collaborate with other professional organizations in chaplaincy, medicine, nursing and social work to expand the knowledge base to other providers who treat seriously ill patients.

• Coalition Members will seek improvements in the palliative care curricula in medical, nursing, social work and chaplaincy schools.

• The Coalition recommends palliative care content be enhanced in medical licensure and specialty board certification in disciplines that treat patients with serious illness (e.g. cardiology/heart failure, oncology, pulmonology/COPD, geriatrics, and neurology/dementia).

• The Coalition represents a field with a core organizational element that is multi-disciplinary. Our Coalition is interested in future inter-professional collaboration and
training opportunities within our own field and with others caring for patients with serious illness.

- There is a significant lack of institutional financial support for inter-professional education for health care providers seeing patients with serious illness. As “experts” in the field of hospice and palliative care, our organizations recognize we have a responsibility to help educate other health care providers in medicine, nursing, social work and chaplaincy about quality primary palliative care.

- The IOM Report recommends that the “Accreditation Council on Graduate Medical Education should require palliative care education and clinical experience in programs for all specialties responsible for managing advanced serious illness”. Our Coalition strongly supports this recommendation. All clinicians who take care of seriously ill patients need to have basic palliative care training and demonstrated competencies.

- The Coalition supports the IOM recommendation that certifying bodies need to require palliative care knowledge, skills, and competency for those providers who take care of seriously ill patients.

- The Coalition supports state licensure efforts for nurses, physicians and social workers who care for those at the end of life to have palliative care training.

**Recommendation # 4 Policies and Payment Systems to Support High Quality End of Life Care**

The Coalition pledges to work with external stakeholders and key opinion leaders to reduce and eliminate the perverse incentives and program misalignments in Medicare, Medicaid, and private insurers that lead to high rates of burdensome transitions between care settings. Major reforms are needed to reduce or eliminate incentives that lead to more use of services (hospital days, intensive care, emergency room care, and ambulances), more burdensome transitions among care settings, and late enrollment in hospice, all of which jeopardize the quality of life for those with serious illness and those at the end of life.

Various medical settings have financial incentives to keep beneficiaries cycled through different care settings and institutionalized even though most people prefer to stay in their homes with the appropriate medical, social, and personal care supports (such as direct care workers, transportation and meal assistance).

- The Coalition supports public policy efforts to improve care coordination across health care settings and providers.
- The Coalition supports efforts to enact meaningful payment reform which would allow beneficiaries improved access to long term services and support with assistance with activities of daily living. (IOM Report, 5-26)
- The Coalition supports efforts to revise the Medicare Hospice Benefit to expand eligibility criteria to 1 year expected mortality and explore policy options for concurrent coverage of disease treatment along with the hospice benefit. The IOM Report clearly demonstrates evidence that many concurrent care models improve patient satisfaction with their health care and also conserve resources. (IOM Report, 5-45)
- The Coalition encourages CMS’s Innovation Center to test new payment and service delivery models towards improving access to both concurrent palliative care and earlier access to hospice.
The Coalition supports public policy efforts to provide caregiving training and support, retrofitting the home for safety and mobility, providing meals and nutrition services, family respite, and transportation services to Medicare beneficiaries and others with serious illness.

The Coalition supports efforts by the Medicare and Medicaid Coordination Office to better coordinate care for the dual eligible population, one of the most vulnerable sectors of the patient population (IOM Report, 5-40).

**Research Recommendations:** There have been a number of pivotal clinical trials demonstrating that both palliative care and hospice improves the patient experience of care (including quality, survival, and satisfaction) and reduces the cost of health care. (IOM Report 5-21). Each section of the IOM Report contains specific areas where additional research is needed. Our Coalition will be recommending to Congress, the National Institute of Health, CMS, Agency for Healthcare Research and Quality, the Veterans Administration, and the Patient Centered Outcomes Research Institute that more dedicated resources should be devoted to palliative care, and end-of-life care, including the needed investment in measure development. This can be accomplished by both increasing federal funding directly for palliative care research but it can also be accomplished by integrating palliative care research questions and reporting of specific components of palliative care into research proposals in cancer, lung, kidney and liver diseases, heart failure, ALS, Alzheimer’s disease/other dementias, Parkinson’s, and in the aging research portfolio in general.

- There are numerous specific research proposals that would benefit not only patient care but also the field of health economics. The Coalition supports the funding and development of these research questions as detailed in the IOM Report. (IOM Report, 5-49). In particular, the following research topic areas need immediate attention.
  - Research is needed to eliminate geographic variations in service utilization and cost.
  - Research is needed to support how best (and by whom) to provide advance care planning services which are conducted by appropriately trained and credentialed individuals, in a manner that is culturally sensitive and appropriate for different patient populations. There are currently no evidence based guidelines, competency requirements, or standards for provider/patient communication or ACP.
  - Research and funding for measure development, testing and validation is needed.

**Recommendation # 5 Public Education and Engagement**

The Coalition supports outreach and engagement with the public regarding quality care for patients with serious illness and those at the end of life and looks forward to partnering and collaborating with other organizations to reach a broader audience about the need to improve care.
Conclusion: The Coalition strongly supports the major findings and recommendations of the IOM Report, *Dying in America* and will focus our efforts to promoting these recommendations within our profession, with external health care and patient advocacy organizations and with federal health care policy makers and government agencies. The goal of hospice and palliative care includes achieving “the Triple Aim” of improving the patient experience of care (including quality and satisfaction); improving the health of populations; and reducing the per capita cost of health care.

**ORGANIZATIONS IN COALITION AND SUPPORTING STATEMENT**

- **American Academy of Hospice and Palliative Medicine (AAHPM)**
- **Association of Professional Chaplains (APC)**
- **Center to Advance Palliative Care (CAPC)**
- **Health Care Chaplaincy Network (HCCN)**
- **Hospice and Palliative Nurses Association (HPNA)**
- **National Hospice and Palliative Care Organizations (NHPCO)**
- **National Palliative Care Research Center (NPCRC)**
- **Social Work Hospice and Palliative Network (SWPHN)**

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