REPORT OF THE BOARD OF TRUSTEES

BOT Report 5-I-16

Subject: IOM "Dying in America" Report
(Resolution 6-I-15)

Presented by: Patrice A. Harris, MD, MA, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws
(John P. Abenstein, MD, Chair)

At its 2015 Interim Meeting, the American Medical Association (AMA) House of Delegates referred to the Board of Trustees Resolution 6-I-15, "IOM 'Dying in America' Report," introduced by the Medical Association of Georgia. Resolution 6 asked our AMA to "support and advocate for the recommendations of the Institute of Medicine 'Dying in America' report, which will improve the quality of end-of-life care received by all patients."

Testimony for this resolution supported the spirit of the IOM report in light of the recognized need to improve quality of care at the end of life. However, testimony noted that the AMA had not had the opportunity to vet the report thoroughly in light of existing AMA policies on relevant issues and noted that endorsing the report in its entirety could have unintended consequences for AMA.

BACKGROUND

The overarching goal of *Dying in America* is to ensure that all patients "with advanced serious illness who are nearing the end of life" have round-the-clock access to comprehensive care provided by appropriately trained personnel in appropriate settings, in keeping with individuals' values, goals, and preferences.

The report identifies five key domains in which action is needed: financing for comprehensive care; quality measurement; professional education, licensure, and credentialing; interoperable electronic health records; and public education about end-of-life care and advance care planning. In each of these areas, the report recommends specific activities and defines accountability among key stakeholders. (See Appendix A.)

Financing for Comprehensive Care

Dying in America calls for public and private payers to cover provision of comprehensive, high-quality consistently accessible care that is "patient centered and family oriented"; consistent with individuals' values, goals, and preferences; and delivered by appropriately trained personnel (Recommendation 1). Such care should include access to interdisciplinary palliative care. The report further recommends that federal, state, and private insurance and health care delivery programs "integrate the financing of medical and social services," by supporting coordination of care and use of financial incentives to decrease use of inappropriate emergency department or acute care services, among other initiatives (Recommendation 4).

Quality Measurement

Dying in America recommends that organizations that deliver health care publicly report aggregate measures of quality and cost for the full range of end-of-life care (Recommendation 1). The report urges professional societies and other organizations to establish, and payers and health care systems to adopt, quality standards specifically relating to patient-clinician communication and advance care planning, toward the goal of ensuring that all individuals have an opportunity to participate in decisions about their care and receive services consistent with their values, goals, and preferences (Recommendation 2). It further calls on the federal government to require public reporting of quality measures, outcomes and costs, for all programs it funds or administers, and to encourage all other payment and delivery systems to do so as well (Recommendation 4).

Professional Education, Licensure and Credentialing

Dying in America recommends that all clinicians who provide care for patients with advanced serious illness should be competent in basic palliative care and that educational institutions and professional societies provide opportunities for lifelong learning in this area (Recommendation 3). Accrediting organizations, certifying bodies, health systems, and regulatory agencies should include training in palliative care in licensure requirements for health care professionals who provide care for patients nearing the end of life, and resources should be committed to increase the number of available training positions for specialty-level training in palliative care.

Interoperable Electronic Health Records

Dying in America identifies the need for "coordinated, efficient, interoperable" transfer of information among all providers and settings of care to support high quality, integrated, comprehensive care (Recommendation 1). It further calls for electronic health records that document advance care planning to improve communication across providers and settings over time, including providing for documentation of designation of a surrogate; patient values, goals, and preferences; the patient's advance directive (when the patient has one); and medical orders for life-sustaining treatment (Recommendation 4). The report also urges states to develop and implement Physician Orders for Life-Sustaining Treatment (POLST) programs "in accordance with nationally standardized requirements."

Public Education about End of Life and Advance Care Planning

Finally, *Dying in America* urges civic leaders, government entities, health care professionals, and other stakeholders to collaborate in developing and disseminating evidence-based information about care and the end of life and advance care planning to counter misinformation and encourage meaningful dialogue (Recommendation 5). The report calls on stakeholders to support research to assess public perceptions and actions, developing and testing effective messaging tailored to target audiences, and measuring progress and results.

AMA POLICY

AMA has extensive policy relevant to end-of-life care and to support the ultimate goals of the *Dying in America* report in all of the domains noted above. (See Appendix B.)

The AMA *Code of Medical Ethics* has strong, well-established guidance that recognizes the importance of engaging patients in advance care planning so that patients' values, goals, and preferences can inform care planning (Opinions 5.1, 5.2). The *Code* calls on physicians to respect

patients' decisions about care at the end of life, including decisions to forgo or withdraw life-sustaining interventions (Opinions 5.3, 5.4). The *Code* encourages physicians to engage pediatric patients (Opinion 2.2.1) and adult patients with compromised decision-making capacity to participate in treatment decisions to the extent possible, and recognizes the important role that surrogate decision makers play when patients lack decision-making capacity (Opinion 2.1.2). The *Code* further provides for the use of sedation to unconsciousness as an intervention of last resort for terminally ill patients when distressing symptoms are refractory to appropriate, symptom-specific palliative care (Opinion 5.6).

Policies of the AMA House of Delegates similarly promote advance care planning and patient-centered decision making at the end of life (H-85.956, H-85.957, H-140.845, H-140.966, H-140.970, H-140.989, D-140.968). House policies also encourage palliative care and hospice for patients nearing the end of life and support education across the professional lifespan in these areas (H-70.915, H-85.955, H-295.875), as well as in areas of medical specialization in which end-of-life decision making can play a central role, such as geriatrics (H-295.981, D-295.969).

In addition, the AMA has adopted policy calling for affordable, interoperative electronic medical records and medical devices to promote more effective coordination of care (D-478.994, D-478.995, D-478.996), as well as policy that addresses essential frameworks for physician maintenance of licensure and maintenance of certification (H-275.917, H-275.924). However, AMA policy opposes tying physician licensure to mandated, content-specific continuing medical education (H-275.973, H-295.921, H-300.953).

AMA PROGRAMS & ACTIVITIES

In addition to extensive policy, the AMA is (or has been) involved in numerous activities and programs designed to improve care at the end of life consistent with the broad recommendations of *Dying in America*. For example, the AMA was instrumental in the development of Education in Palliative and End-of-Life Care (EPEC), a program designed to educate practicing physicians from all specialties in palliative care, which is now offered by Northwestern University Feinberg School of Medicine (EPEC). Journals in the JAMANetwork offer a variety of online CME modules in palliative care and pain management and live educational events at AMA meetings in recent years have addressed communicating with patients for advance care planning [1].

Through its participation in the Liaison Committee on Medical Education (LCME) and Accreditation Committee for Graduate Medical Education (ACGME), the AMA works to promote comprehensive education for physician trainees to ensure that they acquire the knowledge and skills to provide high quality, patient-centered care for a diverse patient population [2, 3]. Through the Physician Consortium for Performance Improvement (PCPI), the AMA has contributed to efforts to define and measure quality in end of life care.

With the American Bar Association, the American Hospital Association, the American Academy of Hospice and Palliative Medicine and numerous other medical specialty societies, the AMA annually supports National Health Decisions Day, an initiative to provide information and resources on advance care planning for both patients and health care professionals.

The AMA has argued for legal recognition of patients' right to control decisions about their care at the end of life, including the right to refuse unwanted life-sustaining treatment [4]. The AMA has advocated for legislative support of advance care planning and advance directives. The AMA's efforts were instrumental in the decision by the Centers for Medicare & Medicaid Services to

include payment for AMA-developed CPT codes for advance care planning services in the 2016 Medicare Physician Fee Schedule (PFS) Final Rule.

The AMA's innovative STEPS Forward program of interactive, online educational modules recently launched a new module, Planning for End-of-Life Decisions with Your Patients, to help physicians help patients convey their wishes about end of life care. The AMA is also a strong advocate for improving the usability of electronic health records, and is collaborating with key stakeholders in digital health to this end (Digital Health).

RECOMMENDATION

The Board of Trustees recommends that the following be adopted in lieu of Resolution 6-I-15 and the remainder of this report be filed:

That our AMA reaffirm the following policies, which collectively promote high-quality, patient-centered care for all patients at the end of life:

- H-70.915, Good Palliative Care
- H-85.955, Hospice Care
- H-85.956, Educating Physicians About Advance Care Planning
- H-85.957, Encouraging Standardized Advance Directive Forms within States
- H-140.845, Encouraging the Use of Advance Directives and Health Care Powers of Attorney
- H-140.966, Decisions Near the End of Life
- H-140.970, Decisions to Forgo Life-Sustaining Treatment for Incompetent Patients
- H-140.989, Informed Consent and Decision-Making in Health Care
- H-275.917, Licensure by Specialty
- H-275.924, Maintenance of Certification
- H-295.875, Palliative Care and End-of-Life Care
- H-295.981, Geriatric Medicine
- H-480.953, Interoperability of Medical Devices
- D-140.968, Standardized Advanced Directives
- D-295.969, Geriatric and Palliative Training for Physicians
- D-478.994, Health Information Technology
- D-478.995, National Health Information Technology
- D-478.996, Information Technology Standards and Costs

(Reaffirm HOD Policy)

Fiscal Note: Less than $500.

REFERENCES

1. Council on Ethical and Judicial Affairs. *Resources in Advance Care Planning*. November 2010.
2. Liaison Committee on Medical Education. *Functions and Structure of a Medical School: Standards for Accreditation of Medical Education Programs Leading to the MD Degree*. March 2016.
3. Accreditation Committee for Graduate Medical Education. *Requirements for Graduate Medical Education in Hospice and Palliative Medicine.* February 2015.
4. Brief for the Am. Med. Ass'n et al. as Amici Curiae Supporting Petitioner, Cruzan v. Dir., Mo. Dep't of Health, 497 U.S. 261 (1990) (No. 88-1503).

APPENDIX A[1]

Recommendations of the Institute of Medicine

Recommendation 1. Government health insurers and care delivery programs as well as private health insurers should cover the provision of comprehensive care for individuals with advanced serious illness who are nearing the end of life.

Comprehensive care should

- be seamless, high-quality, integrated, patient-centered, family-oriented, and consistently accessible around the clock;
- consider the evolving physical, emotional, social, and spiritual needs of individuals approaching the end of life, as well as those of their family and/or caregivers;
- be competently delivered by professionals with appropriate expertise and training;
- include coordinated, efficient, and interoperable information transfer across all providers and all settings; and
- be consistent with individuals' values, goals, and informed preferences.

Health care delivery organizations should take the following steps to provide comprehensive care:

- All people with advanced serious illness should have access to skilled palliative care or, when appropriate, hospice care in all settings where they receive care (including health care facilities, the home, and the community).
- Palliative care should encompass access to an interdisciplinary palliative care team, including board-certified hospice and palliative medicine physicians, nurses, social workers, and chaplains, together with other health professionals as needed (including geriatricians). Depending on local resources, access to this team may be on site, via virtual consultation, or by transfer to a setting with these resources and this expertise.
- The full range of care that is delivered should be characterized by 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. The committee believes that informed individual choices should be honored, including the right to decline medical or social services.

Recommendation 2. Professional societies and other organizations that establish quality standards should develop standards for clinician-patient communication and advance care planning that are measurable, actionable, and evidence-based. These standards should change as needed to reflect the evolving population and health system needs and be consistent with emerging evidence, methods, and technologies. Payers and health care delivery organizations should adopt these standards and their supporting processes, and integrate them into assessments, care plans, and the reporting of health care quality. Payers should tie such standards to reimbursement, and professional societies should adopt policies that facilitate tying the standards to reimbursement, licensing, and credentialing to encourage

- all individuals, including children with the capacity to do so, to have the opportunity to participate actively in their health care decision making throughout their lives and as they approach death, and receive medical and related social services consistent with their values, goals, and informed preferences;

[1] Institute of Medicine. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. Washington, DC: National Academies Press; 2015.

- clinicians to initiate high-quality conversations about advance care planning, integrate the results of these conversations into the ongoing care plans of patients, and communicate with other clinicians as requested by the patient; and
- clinicians to continue to revisit advance care planning discussions with their patients because individuals' preferences and circumstances may change over time.

Recommendation 3. Educational institutions, credentialing bodies, accrediting boards, state regulatory agencies, and health care delivery organizations should establish the appropriate training, certification, and/or licensure requirements to strengthen the palliative care knowledge and skills of all clinicians who care for individuals with advanced serious illness who are nearing the end of life.

Specifically,

- all clinicians across disciplines and specialties who care for people with advanced serious illness should be competent in basic palliative care, including communication skills, interprofessional collaboration, and symptom management;
- educational institutions and professional societies should provide training in palliative care domains throughout the professional's career;
- accrediting organizations, such as the Accreditation Council for Graduate Medical Education, should require palliative care education and clinical experience in programs for all specialties responsible
- for managing advanced serious illness (including primary care clinicians);
- certifying bodies, such as the medical, nursing, and social work specialty boards, and health systems should require knowledge, skills, and competency in palliative care; state regulatory agencies should include education and training in palliative care in licensure requirements for physicians, nurses, chaplains, social workers, and others who provide health care to those nearing the end of life;
- entities that certify specialty-level health care providers should create pathways to certification that increase the number of health care professionals who pursue specialty-level palliative care training; and
- entities such as health care delivery organizations, academic medical centers, and teaching hospitals that sponsor specialty-level training positions should commit institutional resources to increasing the number of available training positions for specialty-level palliative care.

Recommendation 4. Federal, state, and private insurance and health care delivery programs should integrate the financing of medical and social services to support the provision of quality care consistent with the values, goals, and informed preferences of people with advanced serious illness nearing the end of life. To the extent that additional legislation is necessary to implement this recommendation, the administration should seek and Congress should enact such legislation. In addition, the federal government should require public reporting on quality measures, outcomes, and costs regarding care near the end of life (e.g., in the last year of life) for programs it funds or administers (e.g., Medicare, Medicaid, the U.S. Department of Veterans Affairs).
The federal government should encourage all other payment and health care delivery systems to do the same.

Specifically, actions should

- provide financial incentives for
    - medical and social support services that decrease the need for emergency room and acute care services,

    - coordination of care across settings and providers (from hospital to ambulatory settings as well as home and community), and
    - improved shared decision making and advance care planning that reduces the utilization of unnecessary medical services and those not consistent with a patient's goals for care;
- require the use of interoperable electronic health records that incorporate advance care planning to improve communication of individuals' wishes across time, settings, and providers, documenting (1) the designation of a surrogate/decision maker, (2) patient values and beliefs and goals for care, (3) the presence of an advance directive, and (4) the presence of medical orders for life-sustaining treatment for appropriate populations; and
- encourage states to develop and implement a Physician Orders for Life-Sustaining Treatment (POLST) paradigm program in accordance with nationally standardized core requirements.

Medical and social services provided should accord with a person's values, goals, informed preferences, condition, circumstances, and needs, with the expectation that individual service needs and intensity will change over time. High-quality, comprehensive, person-centered, and family-oriented care will help reduce preventable crises that lead to repeated use of 911 calls, emergency department visits, and hospital admissions, and if implemented appropriately, should contribute to stabilizing aggregate societal expenditures for medical and related social services and potentially lowering them over time.

Recommendation 5. Civic leaders, public health and other governmental agencies, community-based organizations, faith-based organizations, consumer groups, health care delivery organizations, payers, employers, and professional societies should engage their constituents and provide fact-based information about care of people with advanced serious illness to encourage advance care planning and informed choice based on the needs and values of individuals.

Specifically, these organizations and groups should

- use appropriate media and other channels to reach their audiences, including underserved populations;
- provide evidence-based information about care options and informed decision making regarding treatment and care;
- encourage meaningful dialogue among individuals and their families and caregivers, clergy, and clinicians about values, care goals, and preferences related to advanced serious illness; and
- dispel misinformation that may impede informed decision making and public support for health system and policy reform regarding care near the end of life.

In addition,

- health care delivery organizations should provide information and materials about care near the end of life as part of their practices to facilitate clinicians' ongoing dialogue with patients, families, and caregivers;
- government agencies and payers should undertake, support, and share communication and behavioral research aimed at assessing public perceptions and actions with respect to end-of-life care, developing and testing effective messages and tailoring them to appropriate audience segments, and measuring progress and results; and
- health care professional societies should prepare educational materials and encourage their members to engage patients and their caregivers and families in advance care planning, including end-of-life discussions and decisions.

All of the above groups should work collaboratively, sharing successful strategies and promising practices across organizations.

APPENDIX B

AMA Policies Relating to End-of-Life and Palliative Care

Policy		Issued
Advance Care Planning		
E-2.191	Advance Care Planning	2011
E-2.225	Optimal Use of Orders-Not-to-Intervene and Advance Directives	1998
D-140.968	Standardized Advanced Directives	2007[1]
H-85.957	Encouraging Standardized Advance Directive Forms within States	2011
H-140.845	Encouraging the Use of Advance Directives and Health Care Powers of Attorney	2014[2]
H-330.891	Payment and Coverage for Voluntary Discussions of End-of-Life Issues	2011
Decisions Regarding Life-Sustaining Treatment		
E-2.20	Withholding or Withdrawing Life-Sustaining Medical Treatment	1984[3]
E-2.201	Sedation to Unconsciousness in End-of-Life Care	2008
E-2.22	Do-Not-Resuscitate Orders	1992[4]
E-8.081	Surrogate Decision Making	2001
E-10.016	Pediatric Decision Making	2008[5]
H-140.966	Decisions Near the End of Life	1991[6]
H-140.970	Decisions to Forgo Life-Sustaining Treatment for Incompetent Patients	1991[7]
H-280.968	Do Not Hospitalize Orders	1993[8]
Symptom Management, Palliative Care & Hospice		
H-55.999	Symptomatic and Supportive Care for Patients with Cancer	1978[9]
H-70.915	Good Palliative Care	2014
H-85.955	Hospice Care	2014
H-85.966	Hospice Coverage and Underutilization	1994[10]
H-165.834	National Pain Care	2010
H-295.875	Palliative Care and End-of-Life Care	2006[11]
Physician Education		
D-295.969	Geriatric and Palliative Training for Physicians	2002[12]
H-85.956	Educating Physicians About Advance Care Planning	2014
H-295.981	Geriatric Medicine	1985[13]
H-295.995	Recommendations for Future Directions for Medical Education	1982[14]
Physician Licensure &Certification		
H-275.997	Licensure by Specialty	1980[15]
H-275.917	An Updated on Maintenance of Licensure	2015
H-275.924	Maintenance of Certification	2009[16]
Health Information Technologies		
D-478.994	Health Information Technology	2005[17]
D-478.995	National Health Information Technology	2004[18]
D-478.996	Information Technology Standards and Costs	2004[19]
H-480.953	Interoperability of Medical Devices	2009[20]
Quality Measures		
H-450.958	Support for Development of Measures of Quality	1997[21]
H-450.966	Quality Management	1994[22]

[1] Reaffirmed 2015
[2] Reaffirmed 2015
[3] Updated 1996
[4] Updated 2005
[5] Updated 2010
[6] Reaffirmed 2013
[7] Reaffirmed 2009
[8] Reaffirmed 2010
[9] Updated 2010
[10] Updated 2014
[11] Amended, Res 322 A-14
[12] Reaffirmed 2012
[13] Amended, Res 301 A-10
[14] Reaffirmed 2011
[15] Reaffirmed 2010
[16] Updated 2015
[17] Reaffirmed 2014
[18] Reaffirmed 2015
[19] Reaffirmed 2014
[20] Reaffirmed 2015
[21] Reaffirmed 2007
[22] Reaffirmed 2015