Dying in America

IOM Report Review

Emphasis on Local Impact

Virginia (Ginger) Marshall MSN, ACNP-BC, ACHPN, FPCN
National Director of Palliative Care
Hospice & Palliative Care Compassus
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“A hurricane of change is made of the things like the beating of a butterfly’s wings”
Dying In America
Study Overview
Statement of Task: Conduct a Consensus Study

**Determine:** Current state of medical care for persons of all ages with a serious illness or medical condition who may be approaching death and require: coordinated care, appropriate personal communication (or communication with parents or guardians for children and individual and family support).

**Assess:**
- The delivery of medical and social care, to both the person approaching death and the family;
- Person-family-provider communication of values;
- Preferences and beliefs;
- Advance care planning;
- Health care costs, financing, and reimbursement;
- Education of health professionals, patients, families, employers, and the public at large.

**Explore** approaches to advance the field.

Committee

Philip A. Pizzo (Co-Chair)  Medicine, Academia
Stanford University
David M. Walker (Co-Chair)  Finance
Former U.S. Comptroller General
Patricia A. Bomba  Payer
Excellus BlueCross BlueShield
Eduardo Bruera  Medicine, Oncology
MD Anderson Cancer Center
Charles J. Fahey  Social Work, Spirituality, Clergy
Fordham University
Milbank Memorial Fund
Pamela S. Hinds  Nursing, Pediatrics
Children’s National Health System
The George Washington University
Karla F.C. Holloway  Law, Cultural Studies
Duke University
Naomi Karp:  Finance, Consumer Protection
Consumer Financial Protection Bureau
Jean S. Kutner  Medicine, Research
University of Colorado
Bernard Lo  Medicine, Bioethics
Greenwall Foundation
Salimah H. Meghani  Nursing, Bioethics, Research
UPenn School of Nursing

Diane E. Meier  Medicine, Public Policy
Center to Advance Palliative Care
Icahn School of Medicine
William D. Novelli  Consumer Empowerment
Georgetown University
Stephen G. Pauker  Medicine, Medical Informatics
Tufts University
tufts Medical Center
Judith R. Peres  Social Work, Long Term Care
Clinical Social Worker/Policy Consultant
Leonard D. Schaeffer  Finance, Payers
University of Southern California
W. June Simmons  Social Work, Nursing
Partners in Care Foundation
Christian T. Sinclair  Medicine, Social Media
University of Kansas Medical Center
Joan M. Teno  Medicine, Academia, Research
Brown University
Fernando Torres-Gil  Medicine, Public Affairs
UCLA
James A. Tulsky  Medicine, Research, Communication
Duke University
“Knowing is not enough; we must apply. Willing is not enough; we must do.”
—Goethe
Care Delivery
and
Clinician-Patient Communication
Findings— Care Delivery

- Multiple transitions between health care settings can fragment delivery of care and create burdens for patients and families
- Demand for family caregiving and the responsibilities of family caregivers are increasing
- Palliative care enhances quality of life, reflects patient choices, and supports families
- Widespread timely referral to palliative care appears slow
Louisville, KY

“The right to be let alone- the most comprehensive of rights and the right most valued by civilized man.”

Justice Louis Brandeis
Recommendation 1 Delivery of Care

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, patient centered, family oriented, 24/7 accessibility
• Consider evolving physical, emotional, social, and spiritual needs
• Include coordinated information transfer across all providers and settings
• Be consistent with individuals’ values, goals and informed preferences

Steps for healthcare organizations to provide comprehensive care
• Access to Palliative Care and or Hospice care in all settings of care
• Interdisciplinary Palliative Care teams
• Transparent and accountable care through public reporting of quality and cost measures

Complete recommendation available at www.iom.edu/endoflife
Recommendation 1  Delivery of Care

What Can You Do?

• Family oriented care
  o Assess impact of treatment goals on involved caregivers

• Transfers across all providers and settings
  o Transfer / Discharge summaries highlighting goals of care
  o Verbal reports to RNs, MDs, Social workers in accepting facilities
  o Copies of POLST forms and living wills

• Spiritual needs
  o Spiritual Assessment…….Universal questions to ask
    ▪ “Where do you find your spiritual and emotional support during this time?”
    ▪ “Is your spirituality a resource to you at this time?”
    ▪ “How are your emotional needs being met?”
  o Triggers for involvement of chaplain support?
  o Offer to involve outside clergy in discussions of treatment goals

• Interdisciplinary Palliative Care
Findings—Clinician-Patient Communication and Advance Care Planning

• Most people nearing the end of life are not physically, mentally, or cognitively able to make their own decisions about care.
  o Advance Care Planning is essential to ensure that care reflects values, goals, and preferences
• Of people who indicate their EOL care preferences, most choose care focused on alleviating pain and suffering.
  o Advance Care Planning and medical orders are needed to ensure these preferences are honored
• Frequent clinician-patient conversations about EOL care values, goals, and preferences are necessary to avoid unwanted treatment.
• Incentives, quality standards, and system support are needed to promote improved communication skills and more frequent conversations.

Complete findings available at www.iom.edu/endoflife
Charleston, WV
Recommendation 2  Clinician-Patient Communication and Advance Care Planning

Professional societies and other organizations that establish quality standards should develop standards for clinician–patient communication and advance care planning (ACP) 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.

Complete recommendation available at www.iom.edu/endoflife
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

- the opportunity for all persons to participate in their health care decision making;
- initiation of ACP conversations and integration of them into care plans; and
- clinician’s revisiting of ACPs

Complete recommendation available at www.iom.edu/endoflife
Develop standards for clinician–patient communication and advance care planning (ACP) that are measurable, actionable, and evidence based.

- University of Utah Center on Aging
- NHPCO's Quality Resource Center
  - [http://www.nhpco.org/quality](http://www.nhpco.org/quality)
- AAHPM
  - [http://aahpm.org/quality/quality-guidelines](http://aahpm.org/quality/quality-guidelines)
- Physician Quality Reporting System (PQRS)
  - [https://www.medicare.gov/physiciancompare/staticpages/data/pqrs.html](https://www.medicare.gov/physiciancompare/staticpages/data/pqrs.html)
Recommendation 2  Clinician-Patient Communication and Advance Care Planning

What Can You Do?

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.

- Review and assess your organization’s policies / guidelines for Advance Care Planning
  - Easily assessable?
  - Standard Location in paper chart or EMR?
  - Transitions of Care?
- QI projects for Advance Care Planning
  - Cancer Care Ontario’s Advance Care Planning toolkit
Professional Education
Findings—Professional Education

• The establishment of specialty practice in hospice and palliative medicine is a major improvement in the education of health professionals.

• Three problems remain:
  o Insufficient attention to palliative care in medical and nursing school curricula
  o Educational siloes the impede development of interprofessional teams
  o Deficits in equipping providers with sufficient communication skills

• Health professionals are not always adequately prepared to deliver “basic” or “primary” palliative care
Recommendation 3 Professional Education

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.

Complete recommendation available at www.iom.edu/endoflife
Recommendation 3  Professional Education

• **All** clinicians who care for people with advanced serious illness should be competent in basic palliative care
• Educational institutes and professional societies should provide training in palliative care
• Accrediting organizations should require palliative care education and clinical experience in programs for all specialties responsible for managing advanced serious illness.
• Certifying bodies should require knowledge, skills, and competency in palliative care
• State regulatory agencies should include education and training in palliative care in licensure requirements
• Create pathways to certification that increase the number of professionals who pursue specialty-level palliative care training
• Commitment of institutional resources to increase the number of available training positions for specialty-level palliative care
Recommendation 3 Professional Education

What Can You Do?

All clinicians who care for people with advanced serious illness should be competent in basic palliative care

- Utah Certificate Of Palliative Care Education At The University Of Utah (UCoPE) [https://continue.utah.edu/proed/palliativecare](https://continue.utah.edu/proed/palliativecare)
  - Four day intensive course designed for mid-career health care providers who want to improve their generalist palliative care skills

Educational institutes and professional societies should provide training in palliative care

- Discuss volunteering your organization as a clinical rotation for students: Medicine, Nursing, Social Work, Pharmacy; Chaplaincy

- HPNA Call to Action
  - AACN: Competencies And Recommendations for Educating Undergraduate Nursing Students (CARES) Preparing Nurses to Care for the Seriously Ill and their Families
Recommendation 3 Professional Education

What Can You Do?

Educational institutes and professional societies should provide training in palliative care

Palliative Care & Hospice Education and Training Act H.R. 3119

• PCHETA Legislation, S. 2847, has been introduced in the Senate by Senator Baldwin (D-WI) on April 5th and Senators Capito (R-WV) and Wyden (D-OR) have co-sponsored.

• PCHETA Virtual Lobby Day, April 27th: Plan social media and/or communication around that day/week for maximum impact.

• PCHETA Lobby Day in Washington, DC, June 22- sponsored by the Patient Quality of Life Coalition:
Recommendation 3 Professional Education

What Can You Do?

Create pathways to certification that increase the number of professionals who pursue specialty-level palliative care training

• Support certification
  o Cover cost of study material, prep courses, carve out prep time, salary differential.

• Get certified!!
  o HPCC: http://hpcc.advancingexpertcare.org/
  o ABMS/AAO/HMDCB: http://aahpm.org/career/certification
  o NASW: www.socialworkers.org/credentials/credentials/achp.asp
  o Board of Chaplaincy Certification Inc. (BCCI)
    o http://bcci.professionalchaplains.org/content.asp?contentid=45

• If certified, volunteer
  o Exam Development Committee
  o Role Analysis Advisory Committee
Policies and Payment Systems and Public Education and Engagement
Most students of any business course are taught constantly about the importance of having a good Return on Investment. Whether
Findings—Policies and Payment Systems

- Incentives under fee-for-service Medicare result in more use of services, more transitions among care settings, and late enrollment in hospice.
- Programs that integrate health care and long-term social services may reduce hospitalizations and health care costs while improving patients’ quality of life.
- Changes are needed throughout the health care system to incentivize provision of comprehensive palliative care.
- Quality standards and measures are needed to ensure that changes in payment systems, particularly those under ACA, do not adversely affect EOL care quality.

Complete findings available at www.iom.edu/endoflife
Recommendation 4: Policies and Payment Systems

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 Department of Veterans Affairs).

The federal government should encourage all other payment and health care delivery systems to do the same.

Complete recommendation available at www.iom.edu/endoflife
Recommendation 4: Policies and Payment Systems

Actions within Policies and Payment Systems should

• Provide financial incentives for:
  o Medical and social support services that decrease the need for emergency room and acute care services
  o Coordination of care across setting and providers
  o Improved shared decision making and advance care planning that reduces the utilization of unnecessary and unwanted medical services

• Require the use of electronic health records that incorporate ACPs
  o Designation of surrogate/decision maker
  o Patient values and beliefs and goals of care
  o Presence of an advance directive
  o Presence of medical orders for life-sustaining treatment

• Encourage states to develop and implement a POLST paradigm program

Complete recommendation available at www.iom.edu/endoflife
Provide financial incentives for medical and social support services, coordination of care across setting and providers, improved shared decision making and advance care planning.


Congress should enact such legislation for [financing of medical and social services to support the provision of quality care consistent with the values, goals, and informed preferences]

- https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/PhysicianFeeSched/Downloads/FAQ-Advance-Care-Planning.pdf

Complete recommendation available at www.iom.edu/endoflife
Findings—Public Education and Engagement

• Need for public education and engagement is manifest at the societal, community/family, and individual levels.
• Most Americans lack knowledge about EOL care choices, and the health community and other leaders have not fully utilized strategies to make that knowledge available, meaningful, and relevant across diverse groups.
• Efforts are needed to normalize conversations about death and dying.
• Several social trends suggest that the time is right for a national dialogue on this issue.

Complete findings available at www.iom.edu/endoflife
Nashville, TN
Atlanta, GA

JUST PASSING THROUGH?
AREN’T WE ALL?

INTERFAITH AIRPORT CHAPLAINCY
ATRIUM THIRD FLOOR AND CONCOURSE E • AIRPORTCHAPEL.COM
Recommendation 5: Public Education and Engagement

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.

Complete recommendation available at www.iom.edu/endoflife
Recommendation 5: Public Education and Engagement

- Use appropriate media and other channels to reach audiences
- Provide evidence-based information about care options
- Encourage meaningful dialogue among individuals, their families, caregivers, clergy, and clinicians about values and goals of care
- Dispel misinformation
- Health care delivery organizations should provide information and materials about care near end-of-life
- 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
- 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 EOL discussions and decisions.

Complete recommendation available at www.iom.edu/endoflife
Recommendation 5  (Continued)

What Can You Do?

Use appropriate media and other channels to reach audiences
• Organization, Community, Church education / in-services
• National Healthcare Decisions Day  4-16-16  http://www.nhdd.org
• Death Café, http://deathcafe.com/
• The Conversation Project: http://theconversationproject.org/starter-kit/intro/
• ZDoggMD Rap Video “Ain’t the Way to Die” about the suffering caused by our failure
to think and talk about our end-of-life wishes early on. http://zdoggmd.com/

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
• Review IOM Death in America Report Organizational Commitment Statements
  o Statements describing organizational goals or commitments to action in one or
    more of the recommendation areas
IOM Report: Dying In America…What’s next?

• The National Academy of Medicine is hosting a working meeting for stakeholders on May 23, 2016, in Washington, DC, to assess national progress toward recommendations from Dying in America:

• IOM has asked stakeholders to complete/promote this [questionnaire](#) about changes to the serious illness care landscape in the past 18 months.
  • Catalogue progress
  • Identify remaining areas of need
  • Results will be shared with participants at the May 23 meeting.

• A new Roundtable on Quality of Care for People with Serious Illnesses at the National Academies of Sciences, Engineering, and Medicine will convene this summer.
A Gift Which Serves as a Reminder

Faith...

Faith is being sure of what we hope for and certain of what we do not see

Hebrews 11:1
Questions and Discussion