Update and Moving Forward

• Connecting the Institute of Medicine’s *Dying in America* Report with CSCKP Strategic Goals
• Update on CSCKP Progress
• Opportunities to Engage in 2015

February 17, 2015
4:00pm ET
Presenters

- **Diane Meier, M.D.**
  Director of the Center to Advance Palliative Care (CAPC), Professor of Geriatrics and Palliative Medicine at the Icahn School of Medicine at Mt. Sinai

- **Alvin Moss, M.D.**
  Director of the Center for Health Ethics and Law and a Professor of Medicine at the Robert C. Byrd Health Sciences Center of West Virginia University

- **Dale Lupu, MPH, Ph.D.**
  Associate Research Professor at George Washington University and lead consultant of Daleview Associates
Today’s Agenda

4:00 – 4:05 Welcome and Opening Remarks
    Alvin Moss, MD

4:05 – 4:20 IOM Report - *Dying in America* overview
    Guest speaker: Diane Meier, MD— 15 min

4:20 – 4:30 Q&A on IOM Report— 10 min

4:30 – 4:45 Coalition updates
    Alvin Moss, MD

4:45 – 5:00 Organizing for action for 2015
IOM Report - *Dying in America* overview

Guest speaker: Diane Meier, MD

Member of the IOM panel
Implications of a new Institute of Medicine report:

Dying in America:
Improving Quality and Honoring Individual Preferences Near the End of Life

Diane E. Meier, MD
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www.capc.org
www.getpalliativecare.org
@dianeemeier
What is the Institute of Medicine?
The IOM exists to secure the services of eminent professionals in examination of policy matters pertaining to the health of the public. The IOM acts under the National Academy of Sciences through its congressional charter as advisor to the federal government.
Why does the IOM matter?
Imprimatur
Legitimacy
Zeitgeist
Awareness
Acceptability
IOM has covered a range of QOL topics

Institute of Medicine Series 2000 to 2014

- Quality cancer care
- Palliative care
- Psychosocial care
- Survivorship care
- Pain care
- End of life

Stopping suffering across the continuum is their common denominator (and ours).
IOM has now made clear (in 6 reports): Palliative care IS essential to quality
What is the impact of an IOM report?
It depends...
Impact depends on:

➔ How effectively stakeholders are able to leverage its findings.
What are the report recommendations?
5 Recommendations

1. Person-centered, family-oriented (palliative) care
2. Clinician-patient communication and advance care planning
3. Professional education and development
4. Policies and payment systems
5. Public education and engagement
1. Delivery of Care

➔ All payers should cover palliative care and all health organizations should provide it.
2. Communication and ACP

- Professional and quality organizations should develop standards for clinician-patient communication and advance care planning that are measurable, actionable, and evidence based.
- Adherence to these standards should be tied to credentialing, licensing, and reimbursement.
“There’s no easy way I can tell you this, so I’m sending you to someone who can.”
3. Professional Education and Development

Establish training, certification, and licensure requirements that strengthen the palliative care knowledge and skills of all clinicians who care for individuals with advanced serious illness…
4. Policies and Payment Systems

➔ Federal, state, and private insurance and health care delivery programs should integrate the financing and delivery of medical and social services;

➔ And require public reporting of quality and costs for care near the end of life.
5. Public Education and Engagement

→ Every element of society should engage their constituents and provide factual 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.
Palliative care when added to usual cancer care benefits people even when they are still receiving chemotherapy. These approaches allow additional discussion of treatment options and provide opportunities to arrive at well-considered decisions. Palliative care may avoid unhelpful but expensive care not only at the end of life, but also throughout the course of the illness. For individuals who have more advanced disease, hospice care may also be appropriate.

spread beyond the lung by process of metastasis into nearby other parts of the body. Most cancers that start in the lung, known as primary lung cancers, are carcinomas that derive from epithelium. The main primary types are small-cell lung carcinoma (SCLC) and non-small-cell lung carcinoma (NSCLC). The most common
Dave Foster and 7 others retweeted

InstituteofMedicine @thelOM · Sep 17

New report—Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life #IOMendoflife ow.ly/BBT2S
QOL advocacy & public awareness campaign: Treating the person beyond the disease

Federal and state legislation

Brig quality of life and care together for the millions facing cancer.
Paired with Health System Engagement

→ ACS account manager PC deployment plans 2015:

- ACS staff are helpful **boots on ground partners** for palliative care integration efforts in cancer centers and health systems.

- ACS staff charge is to boost stakeholder involvement and action – including addressing IOM recommendations and advancing advocacy campaign.
How can we leverage the report’s recommendations to strengthen access to quality palliative care?
Predictors of IOM Report Impact
Opinions of Policy Makers

➔ Predictors of impact according to folks on the Hill and in the legislative branch
➔ Sponsor
➔ Charge
➔ Repetition of a consistent message by all stakeholders
➔ Stakeholder effectiveness as advocates
  – i.e. No circular firing squads!
3 Key Elements of Stakeholder Effectiveness

1. Stories
2. BIG coalition, aligned “asks”
3. Legislative champions with juice
Stories
Fighting to Honor a Father’s Last Wish: To Die at Home

By NINA BERNSTEIN  SEPT. 25, 2014

Maureen Stefanides at NewYork-Presbyterian Hospital with her father, Joseph Andrey, waiting to move to a nursing home despite their efforts to arrange for 24-hour care at his apartment.

Victor J. Blue for The New York Times
# Best Sellers

## Hardcover Nonfiction

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<tr>
<th>#</th>
<th>This Week</th>
<th>Last Week</th>
<th>Title</th>
<th>Author(s)</th>
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<tr>
<td>1</td>
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<td><strong>Killing Patton</strong>, by Bill O'Reilly and Martin Dugard. (Holt.) The host of “The O'Reilly Factor” recounts the death of Gen. George S. Patton in December 1945.</td>
<td><a href="#">Buy</a></td>
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<td><strong>Not That Kind of Girl</strong>, by Lena Dunham. (Random House.) A collection of revealing and often humorous personal essays from the creator and star of “Girls.”</td>
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<td><strong>Being Mortal</strong>, by Atul Gawande. (Metropolitan/ Holt.) The surgeon and New Yorker writer considers how doctors fail patients at the end of life, and how they can do better.</td>
<td><a href="#">Buy</a></td>
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Coalitions
Patient Quality of Life Coalition

ADVANCING THE INTERESTS OF PATIENTS AND FAMILIES FACING SERIOUS ILLNESS BY PROMOTING PUBLIC POLICY TO IMPROVE AND EXPAND ACCESS TO HIGH-QUALITY PALLIATIVE CARE.
Patient QOL Coalition Members

For patient quality of life coalition information: www.patientqualityoflife.org
# What to do?

## Impact vs. Feasibility

<table>
<thead>
<tr>
<th>Low Feasibility</th>
<th>High Feasibility</th>
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<tbody>
<tr>
<td>Low Impact</td>
<td></td>
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<tr>
<td>• Why bother</td>
<td>• Whine and complain</td>
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<td>• Roll your eyes about politics</td>
<td>• Roll your eyes about politics in the U.S.</td>
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<td>in the U.S.</td>
<td>• Talk only with the choir</td>
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<td>High Impact</td>
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<td>• New legislation</td>
<td>• Join effective coalitions</td>
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<td>• Change in CMS regulations,</td>
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<td>Conditions of Participation</td>
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<td>• Sustained public awareness</td>
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<td>campaign</td>
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<td>• WHO resolution</td>
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<td>• Write articles, blogs,</td>
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<td>newsletters</td>
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<td>• Give talks, webinars</td>
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<td>• <em>Explicitly</em> link your work to</td>
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<td>IOM recommendations</td>
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JOB 1

➔ Get our messaging in order with consistent language explaining key recommendations and action steps associated with each of them—messages and action steps to follow.

➔ Identify essential audiences and outlets for outreach in communicating these messages to spread the word broadly.

➔ Take action within and outside our circles to share the messages and press colleagues to do the same so we expand our reach.
Report and Dissemination

- Free slide deck for download
- IOM will engage in 12 month dissemination phase:
  - Materials
  - Stakeholder outreach
  - Evaluating tactics to inform future activities
Type your questions to Dr. Meier into the chat box.
Progress Update
The Coalition for Supportive Care of Kidney Patients (CSCKP) brings together like-minded people who care deeply about the quality of compassionate, supportive care for kidney patients. We are professionals from many disciplines and laypersons who are working for true patient-centered care that values quality of life.

**Mission**

Promote effective interchange among patients, families, healthcare professionals, and payers to ensure the provision of patient-centered supportive care for patients with kidney disease.

**Vision**

Offer palliative care to everyone with chronic and end-stage kidney disease, from the time of diagnosis through the end of life and bereavement. Informed, supported patients and families receive the care they want.

**Goal**

Create culture change that transforms the treatment of persons with kidney disease, putting every patient at the center and integrating palliative principles and practices throughout the care continuum.

**Join the Coalition**

**Subscribe to the Coalition Update**
Progress in 5 Strategic Areas

- Policy
- Quality
- Research
- Education
- Clinical care

& Infrastructure

- Progress builds on member-led activities. CSCPP role is to amplify impact, create synergy.
Policy & Quality

- **Big win** –
  - In response to CSCKP comments during rule-making, CMS issued clear statement preserving current policy that patients with a non-renal terminal illness diagnosis can access concurrent hospice and dialysis payment streams.

- **Incremental actions** –
  - Commented to CMS on QIP quality measures.
  - Signed on to AMA letter to CMS about new Part D regulations inhibiting hospice patients’ access to needed medications. CMS responded by positively revising regulations.
Disappointment – September IOM report on end-of-life care has very little mention of specific kidney supportive care issues, despite Dr. Maloney’s eloquent testimony at June IOM hearing and submission of formal testimony letter.

Demonstrates need for more attention to kidney supportive care.
Visibility - Publications

- O’Hare et al: Patient-Centered Care: An Opportunity to Accomplish the “Three Aims” of the National Quality Strategy in Medicare ESRD. CJASN. December 2014 Note: Written by the CSCKP Executive Committee.
- Grubbs et al: A Palliative Approach to Dialysis Care: A Patient-Centered Transition to the End of Life. CJASN. August 2014.
- Moss & Davison: How the ESRD Quality Incentive Program Could Potentially Improve Quality of Life for Patients on Dialysis. CJASN. In press 2015.
Visibility – Conference exhibit

- Exhibited at November ASN Annual Seminar;
- Offered “meet the expert” curb-side appointments
Research

- USRDS Special Study Center on Palliative and End-of-Life Care – Ann O’Hare, Manjula Kurella Tamura, co-PI’s

- Ongoing discussions with Palliative Care Research Cooperative (PCRC) about development of kidney special interest group.

- KDIGO paper submitted to Kidney International. Follow-up with NINR and NIDDK to request research priority meeting at NIH building on KDIGO.
Specific aims:

1. Evaluate the palliative care needs, quality of communication about end-of-life care, prognostic expectations, and readiness to engage in advance care planning among ESRD patients;

2. Evaluate the end-of-life experience of US adults with ESRD and their families; and

3. Assess the relationship between advance directives and palliative care consultations with downstream healthcare utilization and costs in patients with ESRD.
Education

- Promoting activities of CSKCP members:
  - Visibility for Dr. Weinstein’s clinical decision-making app (RPA with DaVita funding)
  - Visibility for RPA shared decision-making guidelines
  - Visibility for ASN: NephroTalk: Train the Trainers’ Communication Workshop for Nephrology Educators. April 2015, Dr. Schell, ASN GNAG grant

- CSCKP
  - Revised website to include more patient-friendly material
Infrastructure

- Jennifer Ohashi hired 10 hours per week to support CSCKP activities.
- Communication plan completed.
- Over 60 new members have joined as a result of outreach activities.
- Periodic newsletter updates (issues sent June, August, February)
Additional activities underway

- Care plan revision project
- Visibility & Education:
  - Poster at February AAHPM meeting – needs survey of dialysis center staff
  - Response to IOM report
  - Dr. Moss to receive 2015 Medal of Excellence Award from AAKP
Activities Underway

- **Publications in process:**
  - article on dialysis center staff needs assessment survey
  - article on “lessons learned” from oncology adoption of palliative care
  - Article on Steering Committee assessment of progress and priorities on RWJ priorities from 2003
  - article on amount of NIH funding for kidney supportive care research
New projects in development

- Palliative Care Rotation for Nephrology Fellows
- National phone consult service
Sustainability

- Approaching national foundations with interest in:
  - patient-centered care
  - patient engagement
  - palliative care public policy
  - Medical education

- Need leads to:
  - Non-profit insurance plans
  - Corporate funders
Call for Volunteers

Projects available:
- USRDS research study
- Telephone consult service
- Care Planning Committee (Steve Seliger, MD)
- News and Communication (newsletter)
- Membership Outreach
- Policy and Quality
- Fundraising and Development

Please contact Jennifer Ohashi at johashi@nw5.esrd.net if interested.
CSCKP Website

http://www.kidneysupportivecare.org/Home.aspx