The Status of Palliative Care in the United States: An Update

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America's Care of Serious Illness

2015 STATE-BY-STATE REPORT CARD ON ACCESS TO PALLIATIVE CARE IN OUR NATION'S HOSPITALS
Today’s Agenda

• Who are the high risk high cost patients?
• The needs of the seriously ill and their families
• Why palliative care is the solution
• How is our nation doing?
Audience Polling Question

Who is in the audience? (Select your primary role):

A. Palliative care team member
B. Administrator
C. Advocate
D. Researcher
E. Other
What is Palliative Care?

• Specialized medical care for people with serious illness.
  – Doctors, nurses, social workers, chaplains
• Improves quality of life
• Provides an added layer of support
• Accompanies life-prolonging and curative treatments for as long as patients need it.
What Do Palliative Care Teams Do?

**Relieve**
- Pain and other symptoms
- Distress- emotional, spiritual, social, practical
- Uncertainty

**Communicate**
- What to expect
- Treatments that match person and family priorities

**Coordinate**
- Medical and practical needs across settings
Why is Palliative Care the Solution? Many studies show:

- Improved quality of life for patients
  - Reduces pain and other symptoms
  - Addresses patient-family goals
- Improved family satisfaction/well-being
- Prevention of crises that drive hospitalizations and costs

Americans Want Palliative Care*

Telephone survey of 800 Americans

• 92% of respondents say they would seek palliative care for a loved one if they had a serious illness.

• 92% of respondents say palliative care services should be available at all hospitals.

• BUT…Only 8% were knowledgeable about palliative care at the start of the survey

Why a Report Card?

• To determine adequacy of access to palliative care services.
• To understand gaps in access to palliative care delivery to inform policy change.
Audience Polling Question

How have you used the report card up to this point?

A. Forwarded to someone
B. Met with someone to discuss
C. Planned follow-up activities based on the findings
D. All of these activities
E. None of these activities
Methods

• National survey of all hospitals in the United States providing medical/surgical care to adults
• Data linked to American Hospital Association Annual Survey, Dartmouth Atlas of Healthcare, U.S. Census Data
• Full methods available at:
  – http://online.liebertpub.com/toc/jpm/0/0
Did your state make the grade?
>80% of hospitals with palliative care programs
61-80% of hospitals with palliative care programs
41-60% of hospitals with palliative care programs
21-40% of hospitals with palliative care programs
The Good News...
Palliative Care Has Grown Dramatically in U.S. Hospitals

<table>
<thead>
<tr>
<th>Year</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>1998</td>
<td>15</td>
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<tr>
<td>2003</td>
<td>25</td>
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<tr>
<td>2006</td>
<td>53</td>
</tr>
<tr>
<td>2009</td>
<td>63</td>
</tr>
<tr>
<td>2014</td>
<td>67</td>
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</table>
Most regions continue to see growth in palliative care programs.
Who’s Providing Palliative Care?

• 90% of hospitals with 300 or more beds
• 97% of teaching hospitals
• 90% of Catholic Church operated hospitals
• 77% of nonprofit hospitals
Two-Thirds of States Have a Grade of A or B in 2015
Gaps
One-third of U.S. hospitals with fifty or more beds report no palliative care services, and one-third of the states received a grade of C or D.
Where are the gaps?

- **Geography**: the South
- **Ownership**: For Profits
  - All hospitals: 23% of for-profits vs. 67% of nonprofits
  - 300 or more bed hospitals: 54% of for-profits vs. 94% of nonprofits
- **Hospital size**: Smaller hospitals
  - <100 beds: 44% vs. >300 beds: 90%
Percent of Hospitals with Palliative Care Teams by Size

<table>
<thead>
<tr>
<th>Hospital Beds</th>
<th>Percent with Palliative Care Programs</th>
</tr>
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<tbody>
<tr>
<td>50-99</td>
<td>44</td>
</tr>
<tr>
<td>100-199</td>
<td>54</td>
</tr>
<tr>
<td>200-299</td>
<td>71</td>
</tr>
<tr>
<td>300-399</td>
<td>87</td>
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<tr>
<td>400-499</td>
<td>91</td>
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<tr>
<td>500 and above</td>
<td>93</td>
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Graph C. Percentage of hospitals with a palliative care program by hospital beds and regions, 2015

Prevalence of palliative care programs increases with hospital size across regions, with some variation.

MID ATLANTIC
- <50 beds: 23.8%
- 50-150 beds: 47.2%
- 151-300 beds: 73.7%
- 300+ beds: 96.1%

NEW ENGLAND
- <50 beds: 61.0%
- 50-150 beds: 85.0%
- 151-300 beds: 83.8%
- 300+ beds: 96.3%

SOUTH ATLANTIC
- <50 beds: 23.1%
- 50-150 beds: 46.4%
- 151-300 beds: 55.9%
- 300+ beds: 89.0%

EAST NORTH CENTRAL
- <50 beds: 38.2%
- 50-150 beds: 59.2%
- 151-300 beds: 77.3%
- 300+ beds: 94.5%

EAST SOUTH CENTRAL
- <50 beds: 21.6%
- 50-150 beds: 20.3%
- 151-300 beds: 44.4%
- 300+ beds: 75.0%

WEST NORTH CENTRAL
- <50 beds: 27.8%
- 50-150 beds: 52.4%
- 151-300 beds: 70.0%
- 300+ beds: 96.1%

WEST SOUTH CENTRAL
- <50 beds: 19.4%
- 50-150 beds: 26.1%
- 151-300 beds: 39.4%
- 300+ beds: 72.1%

MOUNTAIN
- <50 beds: 24.3%
- 50-150 beds: 53.8%
- 151-300 beds: 71.7%
- 300+ beds: 92.5%

PACIFIC
- <50 beds: 42.2%
- 50-150 beds: 55.9%
- 151-300 beds: 79.8%
- 300+ beds: 96.8%

Number of beds, by color:
- <50: dark blue
- 50-150: light blue
- 151-300: medium blue
- 300+: dark blue

Legend:
- <50 beds
- 50-150 beds
- 151-300 beds
- 300+ beds
Graph D. Percentage of hospitals with a palliative care program by hospital ownership and hospital beds, 2015

Lower rates of palliative care program prevalence persist in for-profit hospitals across all hospital sizes.
## Interpreting Your Grade

<table>
<thead>
<tr>
<th>Grade</th>
<th>Definition</th>
<th>Have Program?</th>
<th>Next Steps/ Interpretation</th>
</tr>
</thead>
<tbody>
<tr>
<td>A/B</td>
<td>&gt;80 percent or &gt;60 percent of hospitals in your state have a PC program</td>
<td>Yes</td>
<td>Congratulations – you’re part of a movement to increase access to palliative care in your state! Next step: Continue to examine the quality of your program.</td>
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<tr>
<td></td>
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<td>No</td>
<td>You are behind many of the other hospitals in your state in delivering this service. Next step: Think about how you would set up a program</td>
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<tr>
<td>C/D</td>
<td>&gt;40 percent or &gt;20 percent of hospitals in your state have a PC program</td>
<td>Yes</td>
<td>Congratulations – you’re leading the way in your state! Next step: Encourage others to do the same and continue to examine the quality of your program.</td>
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<tr>
<td></td>
<td></td>
<td>No</td>
<td>Your state is behind other states in making this service available. Next step: Think about how you would set up a program</td>
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The next 5 years

• Support southern, smaller, and for-profit hospitals to develop palliative care programs

• Enhance access for patients in need
  – <50% of patients who could benefit typically receive palliative care even when it’s available!

• Develop new models of palliative care delivery outside of hospice and hospitals
  – Home, nursing home, office practices
Deficits that need addressing

• Infrastructure
• Workforce
• Evidence
Infrastructure

• Not enough access to palliative care in hospitals with existing programs
• Most illness occurs outside of hospitals
  – Models need to be developed and disseminated without regard to prognosis
• Poor or no quality metrics for complex patients with multiple medical problems moving across multiple care settings.
What is Needed?

• Regulatory and accreditation requirements
• Quality measures linked to payment incentives
• Clinician training in core skills
• System redesign – checklists and pathways
• Insurance benefit design
Quality and Payment

**recommendation:**
Allocate funding to develop quality measures, address communication, concordance, and integration.

**recommendation:**
Direct CMS to include palliative care measures in Medicare Advantage and Medicare Shared Savings programs, accountable Care Organizations, and other quality improvement initiatives.

**recommendation:**
As CMMI is selecting and piloting new care models, ensure that palliative care is a component of care, quality measurement and payment for those with serious illness.

**who should act:**
CMS

**who should act:**
Congress
Work Force

• 1 palliative medicine MD for every 1,700 persons with serious illness

• Most fellowship programs in academic medical centers are supported through philanthropy, not GME

• No mandatory training for front-line doctors and nurses

Morrison et al, IOM, 2011
What Is Needed?

• Palliative care fellowship training
• Training in core palliative medicine knowledge and skills for *all clinicians*
• Quality measures, transparency, and public reporting
Workforce

**recommendation:**

Establish palliative care centers that would develop and disseminate curricula relating to

**recommendation:**

Reform Graduate Medical Education (GME) funding to support residency slots in high-value specialties like palliative care, and explore a GME quality-improvement program to create incentive for skills training in patient-centered communication, team-based care and pain and symptom management for all physicians, regardless of specialty.

**who should act:**

CONGRESS

CONGRESS
Research Funding

• 0.2% of all NIH grants focus on palliative care
• By institute
  – NCI: 0.4% of all grants funded
  – NIA: 0.8% of all grants funded

Gelfman, Du, Morrison, JPM, 2012
The Result:

- Current palliative care practice is guided by:
  - Data from other populations
  - Results from small series of patients from single institutions
  - Anecdote and hearsay

- Is this the type of care that we really want for ourselves and our loved ones?
Support PCORI, NIH and others on symptom relief, communication with serious illness, and palliative care research priorities. These studies should include populations with functional and cognitive impairment. Implementation studies should translate into practice.

**recommendation:**

Develop a Center for Scientific Review (CSR) study section that focuses on serious illness, beyond disease and biology-specific topic areas. Existing study sections that currently review research grant applications related to palliative care should have at least three members with content and methodological expertise in palliative care.

**who should act:**

NIH, AHRQ
What can you do to influence Federal policy?

Talk to your representatives about **HR 3119:** Palliative Care and Hospice Education and Training Act (Engel/Reed)

- Expands federal research
- Supports training for health professionals
- Establishes a national public education and awareness campaign.

State leadership should create a multidisciplinary advisory board and/or task force to conduct a landscape analysis of available palliative care services to determine state capacity and develop State legislatures should appropriate funding to establish palliative care training institutes in their states, ideally within an existing university health system, to develop appropriate curriculum, create requirements for training and provide opportunities for hands-on professional development. The institute should integrate this curriculum into undergraduate and graduate courses in medicine, nursing, social work and chaplaincy. The institute should also provide continuing education for practicing midcareer health care professionals.
## How to Leverage the Report Card?

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<th>Establish Goals</th>
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<td>• Develop a palliative care program in a hospital that does not have one</td>
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<td>• Expand your palliative care program in the hospital/into the community</td>
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<td>• Increase recognition of/funding for palliative care at state level</td>
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<td>• Support passage of the Palliative Care and Hospice Education and Training Act (H.R. 3119)</td>
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<thead>
<tr>
<th>Identify Audience</th>
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<tbody>
<tr>
<td>• Hospital administrators</td>
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<td>• State legislatures</td>
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<tr>
<td>• State health departments</td>
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<tr>
<td>• Federal legislators</td>
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<th>Take Action</th>
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<td>• Schedule meetings with hospital administrators/C-suite to share findings</td>
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<td>• Bring to state coalition or organization to develop state strategy</td>
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<td>• Reach out to state Medicaid department to share information on PC cost/quality</td>
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<td>• Work with local American Cancer Society-Cancer Action Network chapter on passing state advisory board legislation</td>
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<tr>
<td>• Reach out to Federal legislators (letter writing/in-person meeting)</td>
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Community Health Needs Assessment

If your hospital is nonprofit, IRS tax code requires conduct of a community health needs assessment (CHNA) to maintain tax exempt status. Therefore, find out who is responsible for conducting the CHNA in your hospital:  
https://www.irs.gov/Charities-&-Non-Profits/Charitable-Organizations/New-Requirements-for-501%28c%29%283%29-Hospitals-Under-the-Affordable-Care-Act
Community Health Profile Resources

• County Health Rankings
  – http://www.countyhealthrankings.org/

• Community Health Status Indicators
  – http://wwwn.cdc.gov/communityhealth

• Kaiser State Health Facts
  – http://kff.org/statedata/
Thank you to the Cambia Health Foundation

www.cambiahealthfoundation.org
Acknowledgments

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Questions and Comments

• Do you have questions for the presenter?

• Click the hand-raise icon (👋) on your control panel to ask a question out loud, or type your question into the chat box.