PALLIATIVE CARE IN THE AGE OF HEALTHCARE REFORM

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Objectives

After the presentation, participants will be able to:

• Recognize the role palliative care plays in the care of patients with serious illnesses.
• Incorporate basic principles of palliative care into their clinical practice.
• Identify 2 clinical conditions in their service area warranting consultation by the specialty of palliative care.
Introduction

• Big Changes in America’s healthcare system
  – Decades of fee-for-service medicine -> crisis of value
    • Highest per-capita spending on healthcare in the world without better results
    • Focus now is on how to achieve quality vs quantity of services
    • Patients, families, policy makers and payers are demanding change

[CAPC, 2015]
Urgent Crisis

• Sickest and most complex patients fall through cracks in our system
  – Baby Boomer generation = growing population of patients living longer with serious and chronic illness
  – Millions of Americans have serious illnesses and numbers are expected to grow over next 25 yrs
  – Rate of growth of current healthcare expenditures is unsustainable
• 50% of family members of hospitalized loved ones report less than optimal care
• Patients enduring untreated and recurrent pain and other distressing symptoms
• Needs not being met in community so resort to 911 calls and ED visits -> lengthy hospitalizations

[Teno, 2004]
Complex Pts in Hosp

- Hospital-acquired infections
- Medical errors
- Falls
- Delirium
- Complications
- Costliest setting of care

[IOM, 2014]
“High Cost 5%”

- 5% of Medicare beneficiaries account for 50% of Medicare spending
  - Only 11% of that 5% are in their last year of life
  - Many do not qualify for hospice
  - 50% will have major surgeries and recover
  - 40% will have persistent high spending due to life-limiting condition but aren’t dying
    - Dementia
    - Frailty
    - Functional dependency

[IOM, 2014]
Palliative Care

- Specialized medical care for people with serious illnesses
- Focus on relief of pain and symptoms of distress
- Team-based, interdisciplinary approach
- Focus on improving quality of life
- Determining PATIENT Goals of Care
  - Skilled communication
  - Symptom relief
  - Care coordination
## Hospice vs PC

<table>
<thead>
<tr>
<th>Hospice</th>
<th>Palliative Care</th>
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<tbody>
<tr>
<td>• No further curative approaches</td>
<td>• Co-exist with curative therapies</td>
</tr>
<tr>
<td>• ≤6 mo left to live</td>
<td>• Incorporated at dx</td>
</tr>
<tr>
<td>• Daily reimbursement is low [$130/day]</td>
<td>• Can be reimbursed at full rate</td>
</tr>
<tr>
<td>• Lack of experienced pediatric clinicians</td>
<td>• Training incorporated into all disciplines</td>
</tr>
<tr>
<td>• Difficult for primary provider to guide care</td>
<td>• Primary care provider remains in control</td>
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</table>
A Brand Challenge

• Partnership with curative approaches not just when cure fails
• Foundations of integrated good care
• PC: fear it is too early, then find it is too late
Palliative Care

• Model for all of healthcare: holistic, family centered and interdisciplinary
• “Care I want for my mother, myself and everyone”
• PC = the Standard of Care for people with serious illness
• Immoral and unacceptable not to deliver this type of care

[Meiers, 2016]
National PC Registry (2015)

- 90% of U.S. Hospitals with >300 beds have PC services
- Only 3.4% of admissions receive PC
- Estimated 7.5-8% need PC
- 1-1.8 million patients admitted each year could benefit from PC but are not receiving it
PC Differences in Peds/Perinatal

- Trajectories of illness
- Effective pain/sx management RX
- Clinical models of care delivery
- Funding mechanisms
- Research paradigms
- Educational initiatives
- Communication strategies
- Ethical concerns
- Staffing rations and management

[NHPCO, 2015]
“I wish staff had advised us to take more pictures, even when he was so poorly. We have so few and memories change with time.” 1

“... the first day I saw him wearing clothes whilst he was still alive, was just worth more than gold and I will never forget how he looked that day.” 1

“Parents were struggling to comprehend their loss and make sense of their feelings. Their shock meant that thinking straight was almost impossible. Simple discussions became impossible.” 1

Amer. Academy of Peds Core Commitments PC, 2013

- Patient centered and family engaged
- Respecting and partnering with pt/family
- Care that is high quality, readily accessible and equitable
- Care across the age spectrum, life span; integrated into the continuum of care
- All clinicians can provide basic PC with specialists consulted in a timely manner
- Improving care through research and QI
Cost-Related OC of PPC

- Partners for Children [CCS Program]
- UCLA Study 2012
- 11% [$1677] reduction in monthly cost per patient
- 32% reduction in avg. number of days in hospital
- <stress and sleep disturbance and > confidence in ability to care for child

[Ghans, 2012]
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. PC can help address multifaceted aspects of care for patients facing a serious illness:
   - Physical
   - Emotional
   - Social
2. PC is appropriate at any stage of serious illness
   - Frequently offered after all disease-modifying interventions have been exhausted
   - Ideally should be component of care throughout the trajectory of a serious illness
   - Benefits patients, families and caregivers
   - Increased invasive interventions in late stages of disease does NOT prolong survival or improve QOL

[Wright, 2008]
3. Early integration of PC is the new Standard of Care for patients with advanced cancer

- Improved clinical outcomes and longer lives [Tennel, 2010]
- Component of cancer-targeted therapy
- Recommended by:
  - American Society of Clinical Oncology
  - National Comprehensive Cancer Network
  - World Health Organization
  - Oncology Nurses Society
4. **PC can be beneficial for many chronic diseases; per Specialty Societies**
   - “**PC is Standard of Care for serious, complex conditions**” [Meier, 2016]
   - **Conditions with heavy symptom burdens**
     - COPD
     - CHF
     - Pulmonary hypertension
     - End-Stage renal disease
     - Neurodegenerative diseases
5. PC Teams manage total pain

- Functional status and QOL impacted
- Incidence of pain in serious illnesses besides cancer underappreciated
- Require training and expertise in pain syndromes
- Interventional pain clinicians
- Collaborative with Pain Specialists
6. PC manages non-pain symptoms

- Nausea
- Delirium
- Fatigue
- Dyspnea
- Effect of these symptoms on caregivers
7. PC helps address the emotional impact of serious illness on pts/families

- Psychological distress
- Impaired QOL
- Preparatory grief
- Depression
- Psychological and Spiritual support
  - Mood
  - Sense of hope
  - QOL
  - Opportunity to express hopes, worries and meaning of illness
8. PC can assist with complex communication interactions

- Pt-centered, empathic communication between HCP and pts
  - Improve pt satisfaction
  - Adherence to therapy
  - Health outcomes

- Therapeutic presence

- Eliminating non-helpful phrases:
  - “Nothing more we can do”
  - “Withdrawing care”
  - “Doing everything”
9. Addressing barriers to PC: Pt hopes and values = more than a cure

- Worry that PC = beginning of end
  - Fear of taking away hope
  - Early discussions re: illness, wishes and benefits/burdens of disease modifying RX -> better decisions re types of RX pt wish to receive (Fried, 2002)
  - No psychological harm and improved QOL and family bereavement (Wright, 2008)
  - 90% believed PC should be available along side curative approaches. (CAPC, 2011)
10. PC enhances healthcare value

- HC \( \uparrow \$$ = better care at EOL
- PC = cost savings of \$1700\) per admission for pt who survive hospitalization and \$5000\) per admission for those who do not survive.
- Significant \( \downarrow \) in Pharm, lab and ICU $$
- Cost avoidance
- Cost improvement with improved QOL, mood and pt/family satisfaction
Cost Avoidance Estimates

According to evidence based research, there is an estimated cost avoidance of $1,700 per consult [2014+].

<table>
<thead>
<tr>
<th>Year</th>
<th>No. Peds Consults</th>
<th>Cost Avoidance Per Consult</th>
<th>Total Cost Avoidance</th>
</tr>
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<tbody>
<tr>
<td>FY12</td>
<td>592</td>
<td>$1,400 (2011-2013 Estimate)</td>
<td>$828,800</td>
</tr>
<tr>
<td>FY13</td>
<td>684</td>
<td>X $1,400</td>
<td>$957,600</td>
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<tr>
<td>FY14</td>
<td>481</td>
<td></td>
<td>$817,700</td>
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PC = Better Quality + < Costs

- Access limited mostly to hospitals and for those who are dying soon [hospice]
- PC needs to be available to the much larger population of the seriously ill receiving care in community settings
- Single largest opportunity to improve value in US health system
- Desired by patients and families

[CAPC, 2015]
Evidence of value of PC Communication

• Only half of all pts discussed hospice with any doctor 2 months before death
  (Huskamp, 2009)

• 69% of pts/lung cancer and 81% pts/colorectal cancer did not realize chemo could not cure them
  (Weeks, 2012)

• 64% pts/lung cancer did not understand that XRT would not likely cure them
  (Chen, 2013)
“There’s no easy way I can tell you this, so I’m sending you to someone who can.”
“You’re short on ears and long on mouth.” (John Wayne)

People want to know the same 5 things:

What is your understanding of your situation?
1. Name the diagnosis,
2. natural history,
3. prognosis,
4. symptoms, and
5. what caused it?

The Hopkins palliative care communication tattoo

1. How do you like to get medical information?
2. What is your understanding of your situation?
3. What is important to you?
4. What are you hoping for?
5. Have you thought about a time when you could be sicker...Living Will or advance directive?

Communication Pearls

• Significant difference in importance of religion for pt/surrogate vs MD and this impacts family conferences

• Watching CPR video prior to decision making yields significant differences

• Palliative chemo does not improve and actually harms QOL during last wk of life

• While the majority of Americans over 60 believe doctors know what is best for them, the majority under age 40 believe the answer is on the intranet
Jersey Post checks on elderly daily
1/6th of Americans have access to Physician Assisted Death

Aid in dying legislation in the United States

<table>
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<tr>
<th>States with Legislation</th>
<th>Term used in legislation</th>
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<tbody>
<tr>
<td>Oregon Death with Dignity Act – implemented 1997</td>
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</tr>
<tr>
<td>Vermont – 2013</td>
<td>Patient Choice at End of Life</td>
</tr>
<tr>
<td>California – 2015</td>
<td>Aid in Dying</td>
</tr>
<tr>
<td>Montana – state supreme court ruling 2009</td>
<td>Physician aid in dying</td>
</tr>
<tr>
<td>New Mexico – 2014 (law under review)</td>
<td>Aid in Dying – under review with much debate about terminology</td>
</tr>
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Barriers to PC Access

• Workforce
• Research
• Payment models linked to quality measures

Legislation pending in Congress to facilitate research, professional development and public education.

(CAPC, 2015)
Workforce

• All healthcare team must be trained in basics of PC (Wallace, 2015)
• PC is a subspecialty for more complex cases and to support basic team
• PC centers develop and disseminate curricula, support training and CE
• Career incentive awards: certification in PC
• Reform Graduate Medical Education
Research

• PCORI, NIH and AHRG supporting research on symptom relief, communication developing and evaluating models of care delivery

• Specific program RFA targeting populations with functional and cognitive impairment and frailty.

• Center for Scientific Review NIH/AHRQ: Section focusing on non-biological aspects of disease = PC
Quality and Payment

- CMS/Congress: Develop quality measures addressing communication, concordance of treatment with pt preferences and goals of care and transitions across settings and lifetime.
- PC will be included in quality and value-based programs in Medicare-sponsored ACO: process and outcome measures.
- New care models: ensure PC is component of care, QM and payment.
State Level Action: CA

- Sept, 2014: DHCS to establish standards for Medi-Cal managed-care plans to ensure PC services
- Cal State Univ (7 campuses): Statewide Institute for PC
  - Professional development opportunities
  - Online certificate programs for RN, SW, Chap, etc
  - Integrates PC into 30 grad/undergrad courses
  - >2000 educated in first 2 yrs
PC Triggers

• Assistance with complex symptom management
• Care of severely ill pts over time
• Assistance with medical decision making and determining goals of care
• Questions regarding future planning needs
CONCLUSION

• PC improves the QOL of patients with serious illness and their families
• Model of care centered on reducing symptom burden, attending to psychosocial needs, and working to align care with pt/family goals
• Appropriate at any stage of serious illness
• More effective and efficient care associated with cost savings, not less care!
TAKE HOME MESSAGE

PALLIATIVE CARE DRIVES VALUE IN EVOLVING HEALTH CARE PAYMENT MODELS!