Palliative Care in 2018
Making Palliative Care Sustainable for the Future: Advocacy, Workforce and Research

Christian T Sinclair, MD, FAAHPM
Summer 2018

Contacts & Background

• University of Kansas Health System
  – Assistant Professor
  – Division of Palliative Medicine
  – Lead, Outpatient Palliative Care – Oncology
• Pallimed – Editor-in-Chief
• AAHPM – Past President
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• Twitter - @cts Sinclair

Disclaimers

• Aspire Healthcare – KC Metro Lead MD
• Member of the National Academy of Medicine Roundtable on Quality Care for People with Serious Illness
• No pharmaceutical funding
Outline of the Next Two Hours

- Assess the current state
- Innovation
- Action

Pop Density (2010)

Sources: US Census Bureau via Wikipedia

Frontier and Remote (FAR) Level 1 ZIP Code Areas, 2010
Social Determinants of Health (SDoH)

<table>
<thead>
<tr>
<th>Economic Stability</th>
<th>Neighborhood and Physical Environment</th>
<th>Education</th>
<th>Food</th>
<th>Community and Social Context</th>
<th>Health Care System</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employment</td>
<td>Housing</td>
<td>Literacy</td>
<td>Hunger</td>
<td>Social integration</td>
<td>Health care</td>
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<tr>
<td>Income</td>
<td>Transportation</td>
<td>Language</td>
<td>Access to</td>
<td>Support systems</td>
<td>Coverage</td>
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<td>Expenses</td>
<td>Safety</td>
<td>Early childhood</td>
<td>Healthy</td>
<td>Community engagement</td>
<td>Provider availability</td>
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<td>Debt</td>
<td>Parks</td>
<td>education</td>
<td>options</td>
<td>Discrimination</td>
<td>Provider</td>
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<td>Medical bills</td>
<td>Playgrounds</td>
<td>vocational</td>
<td>Stress</td>
<td>Quality of care</td>
<td>linguistic and cultural competency</td>
</tr>
<tr>
<td>Support</td>
<td>Walkability</td>
<td>training</td>
<td></td>
<td></td>
<td>Quality of care</td>
</tr>
<tr>
<td></td>
<td>Zip code / geography</td>
<td>higher-</td>
<td></td>
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<td></td>
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**Health Outcomes**
- Mortality
- Morbidity
- Life Expectancy
- Health Care Expenditures
- Health Status
- Functional Limitations

Source: Kaiser Family Foundation

SDoH Impact on Early Death

- Health and Well Being: 30%
- Individual Behavior: 40%
- Social and Environmental Factors: 20%
- Genetics: 10%
- Health Care: 10%

Source: Schroeder, 2007, NEJM

Insurance Landscape (2016)

- Employer – 51%
- Medicaid – 15%
- Medicare – 17%
- Uninsured – 8%
- Non-group – 8%

- Three Largest Commercial
  - BCBS of KC – 29%
  - Anthem – 29%
  - UnitedHealth Group – 22%

Source: KFF, 2016
2015 Hospice Utilization - MO

- 113 hospice providers
- 31,819 hospice beneficiaries
- 2,190,197 total hospice days
- $325 million
- 48% of all deaths occur with hospice
Opioid Scripts per 100 People

- Source: CDC

Missouri Final State to Implement PDMP

Missouri Governor Signs Executive Order for a statewide Prescription Drug Monitoring Program

- Source: Missouri Governor

[Map showing opioid scripts per state]
Scope of Practice - NP

Source: Center to Advance Palliative Care 2015 Report Card
67%  75%  73%

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<tbody>
<tr>
<td></td>
<td>Rank</td>
<td>Score</td>
<td>Rank</td>
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<tr>
<td>Nevada</td>
<td>C</td>
<td>40.5</td>
<td>C</td>
</tr>
<tr>
<td>Minnesota</td>
<td>B</td>
<td>51.0</td>
<td>A</td>
</tr>
<tr>
<td>Missouri</td>
<td>D</td>
<td>67.5</td>
<td>A</td>
</tr>
<tr>
<td>North Dakota</td>
<td>B</td>
<td>62.7</td>
<td>A</td>
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Source: Center to Advance Palliative Care: 2015 Report Card

National POLST Program Designations
As of April 2018

NATIONAL TRENDS
Moving ACP Upstream

“\(^\text{I have an advance directive, not because I have a serious illness, but because I have a family.}\)"

Ira Byock, MD

Into the Community

• Research shows triple aim benefits
  – Patient exp, population health, reduce cost
• Payor-provider partnerships
  – Aetna Compassionate Care
  – Aspire Health
  – Turnkey Health
  – Landmark Health
• Partner with Home-Based Primary Care
• Advanced Illness Management

FIG. 1. Average Medicare Part A, B, D spending by month before death (home-based palliative care vs. control).

Lustbader, J Palliative Med. 2017
Lustbader, J Palliative Med, 2017

<table>
<thead>
<tr>
<th>Outcomes</th>
<th>Control group (N=500)</th>
<th>Home-based palliative care (N=50)</th>
<th>p</th>
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</thead>
<tbody>
<tr>
<td>Hospital admissions/1000 patients in final month of life</td>
<td>46/44</td>
<td>30/17</td>
<td>0.0221</td>
</tr>
<tr>
<td>ER visits/1000 patients in final month of life</td>
<td>1987</td>
<td>108</td>
<td>0.3882</td>
</tr>
<tr>
<td>Hospice utilization rate (%)</td>
<td>21(58%)</td>
<td>47(82%)</td>
<td>0.0003</td>
</tr>
<tr>
<td>Median LOS</td>
<td>25</td>
<td>14</td>
<td>&lt;0.0001</td>
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*Long-term care resident hospice statistics with LOS >180 days removed from control group (N=50).
Important Issues to Consider

- Social
- Workforce
- Advocacy

Social
- Public need
- Stigma vs acceptance

Clinician demand
- Public demand
- Services to care

The Nation’s Median Age Continues to Rise
Informed Consideration for PC

CAPC Public Opinion Research, 2011
Patients with advanced cancer, whether inpatient or outpatient, should receive dedicated palliative care services, early in the disease course, concurrent with active treatment.

If palliative care is “We’ve got to get into some palliative care,” I’m going to say, “Whoa.” I hope I never hear that.

You’d never get him into palliative care first of all (laughter), but I think it would have to be . . . I don’t know. He would be a difficult case, . . . like something would have to completely debilitate him before he would even consider the option of palliative care.
Social

Public need
Stigma vs acceptance

Public demand

Clinician demand
to care
services

Workforce

New clinicians/yr
Scope of practice

Standards & Training

Benefits

Equity

Projected Supply Compared to Need for HPM Physicians

Source: Lupu, JPSM, 2018
Final List of HPM Entrustable Professional Activities

1. Provide comprehensive pain assessment and management for patients with serious illness
2. Provide comprehensive nonpain symptom assessment and management for patients with serious illness
3. Manage palliative care emergencies
4. Estimate and communicate prognosis to aid medical decision-making
5. Establish goals of care based on patient and/or family values and specific medical circumstances
6. Participate as a member or leader of an interdisciplinary team
7. Prevent and mediate conflict and distress over complex medical decisions
8. Manage withdrawal of advanced life-sustaining therapies
9. Care for imminently dying patients and their families
10. Address requests for hastened death
11. Support patients and families in the psychosocial domain
12. Support patients and families in the spiritual and existential domain
13. Promote self-care and resilience
14. Facilitate transitions across the HPM continuum of care
15. Fulfill the role of a hospice medical director
16. Provide HPM consultation and team support
17. Promote and teach hospice and palliative care

Palliative Care Action Community

- California Health Care Foundation

**Participant Affiliations**

- Small or single-hospital health systems (5 teams)
- Multihospital or regional health systems (7 teams)
- Home health and/or hospice agencies (9 teams)
- Medical groups or specialty palliative care practices (5 teams)

**Program Setting**

- Clinic (5)
  - Home-based (10)
  - Distance/home support (5)

**Annual Volume**

30 to 2,400 patients per program

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**Table 1. Palliative Care Services Offered by PCAC Members, by Setting**

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<thead>
<tr>
<th>Service</th>
<th>CLINIC</th>
<th>HOME-BASED</th>
<th>DISTANCE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advance care planning</td>
<td>100%</td>
<td>100%</td>
<td>60%</td>
</tr>
<tr>
<td>Symptom management</td>
<td>100%</td>
<td>100%</td>
<td>80%</td>
</tr>
<tr>
<td>Emotional support</td>
<td>100%</td>
<td>82%</td>
<td>100%</td>
</tr>
<tr>
<td>Spiritual support</td>
<td>63%</td>
<td>55%</td>
<td>40%</td>
</tr>
<tr>
<td>Medication management</td>
<td>100%</td>
<td>91%</td>
<td>80%</td>
</tr>
<tr>
<td>Information about disease/prognoses</td>
<td>100%</td>
<td>91%</td>
<td>80%</td>
</tr>
<tr>
<td>Referrals to community services</td>
<td>88%</td>
<td>100%</td>
<td>60%</td>
</tr>
<tr>
<td>Case management</td>
<td>31%</td>
<td>64%</td>
<td>40%</td>
</tr>
</tbody>
</table>

Source: Survey of Palliative Care Action Community members, 2013.
### Table 5. CBPC Clinic Staffing Among PCAC Members
*FTE Allocation, by Discipline*

<table>
<thead>
<tr>
<th>Discipline</th>
<th>MIN</th>
<th>MEDIAN</th>
<th>MAX</th>
</tr>
</thead>
<tbody>
<tr>
<td>MD/DO (n=11)</td>
<td>0.10</td>
<td>0.25</td>
<td>1.20</td>
</tr>
<tr>
<td>APN/PA (n=6)</td>
<td>0.08</td>
<td>0.33</td>
<td>1.00</td>
</tr>
<tr>
<td>SWCM/CC (n=6)</td>
<td>0.10</td>
<td>0.26</td>
<td>0.50</td>
</tr>
<tr>
<td>RN (n=5)</td>
<td>0.10</td>
<td>0.30</td>
<td>1.00</td>
</tr>
<tr>
<td>Psychologist/LCSW (n=5)</td>
<td>0.20</td>
<td>0.50</td>
<td>1.00</td>
</tr>
<tr>
<td>Chaplain (n=2)</td>
<td>0.10</td>
<td>0.25</td>
<td>0.40</td>
</tr>
<tr>
<td><strong>Total FTEs (n=11)</strong></td>
<td><strong>0.25</strong></td>
<td><strong>0.90</strong></td>
<td><strong>3.50</strong></td>
</tr>
</tbody>
</table>

*Of those reporting some FTE for that discipline, excluding those who reported 0% FTE.
Note: See page 4 for abbreviation definitions.
Source: Survey of Palliative Care Action Community members, 2014.

### Table 7. CBPC Home-Based Program Staffing Among PCAC Members, FTE Allocation, by Discipline*

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<tr>
<th>Discipline</th>
<th>MIN</th>
<th>MEDIAN</th>
<th>MAX</th>
</tr>
</thead>
<tbody>
<tr>
<td>SWCM/CC (n=8)</td>
<td>0.25</td>
<td>0.55</td>
<td>6.00</td>
</tr>
<tr>
<td>MD/DO (n=6)</td>
<td>0.05</td>
<td>0.38</td>
<td>1.50</td>
</tr>
<tr>
<td>APN/PA (n=5)</td>
<td>0.25</td>
<td>1.00</td>
<td>2.00</td>
</tr>
<tr>
<td>RN (n=5)</td>
<td>0.80</td>
<td>3.00</td>
<td>13.10</td>
</tr>
<tr>
<td>Chaplain (n=3)</td>
<td>0.20</td>
<td>0.25</td>
<td>0.45</td>
</tr>
<tr>
<td>Other (n=1)</td>
<td>2.50</td>
<td>2.50</td>
<td>2.50</td>
</tr>
<tr>
<td><strong>Total FTEs (n=10)</strong></td>
<td><strong>0.50</strong></td>
<td><strong>2.23</strong></td>
<td><strong>19.35</strong></td>
</tr>
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*Of those reporting some FTE for that discipline, excluding those who reported 0% FTE.
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Source: Survey of Palliative Care Action Community members, 2014.
Expected Average Income by Census Region (Q3.5 x Q3.2)

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<tr>
<th>Census region</th>
<th>Average total gross income by census region ($)</th>
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<tbody>
<tr>
<td>1. Northeast</td>
<td>170,800</td>
</tr>
<tr>
<td>2. Midwest</td>
<td>201,800</td>
</tr>
<tr>
<td>3. South</td>
<td>167,200</td>
</tr>
<tr>
<td>4. West</td>
<td>193,800</td>
</tr>
<tr>
<td>All</td>
<td>183,000</td>
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AAHMP Workforce Study, 2016

Fig. 1. Ratio of hospice and palliative medicine physicians to older population. HPM, hospice and palliative medicine; N/A, not applicable.

Lupu, JPSM, 2018
Four Opportunities for Community-Based Palliative Care Billing

Maximize Palliative Care and Advance Care Planning Opportunities!

PATIENT AND CAREGIVER SUPPORT FOR SERIOUS ILLNESS: PATIENT ELIGIBILITY

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Four Opportunities for Community-Based Palliative Care Billing

Maximize Palliative Care and Advance Care Planning Opportunities!

PATIENT AND CAREGIVER SUPPORT FOR SERIOUS ILLNESS: PATIENT ELIGIBILITY

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Four Opportunities for Community-Based Palliative Care Billing

Maximize Palliative Care and Advance Care Planning Opportunities!
Palliative Care Improves Quality of Life

Economics
- New codes
- Cost savings (?)
- PC improves QoL
- Funding driver
- Quality measures

Advocacy
- Social
- Political
- Org
The future of palliative care

In many respects, we’re aligned. Not that we know care won’t get us to the next level. So I’m looking for signals from the future. It’s exciting, isn’t it, Ben?

No, it’s exciting. It’s exciting, you’re right.
Social Advocacy

- What does the public care about?
  - Current conversations about illness
  - Death positivity movement
  - Patient advocacy and patient rights
- What is the world saying about us?
- What are we saying about ourselves?
  - Can you add to the conversation?
ACS-CAN Palliative Care Council

- 2018
  - Kansas, West Virginia
- 2017
  - Maine, Missouri, Montana, Nebraska, Nevada, Ohio, Tennessee
- 2016
  - Alabama, Oregon
- 2015
  - Massachusetts
- 2014
  - Rhode Island
Political Advocacy

• Think on the state and national level
• Any successes or setbacks?
• Touchy subject but everyone has a story
• Calling your legislators is suddenly cool
• If you don’t tell your exp. bus drivers will
• Check with your org and professional societies – follow the rules, use resources
A Model to Improve Value: The Interdisciplinary Palliative Care Services Agreement

Karin Porter-Williamson, M.D., Marilyn Parker, M.S.N., A.C.H.P.N., A.C.N.S., B.C., Stewart Balbott, M.D., Patrick Steffen, M.A.S.A., C.P.C., and Steven Sites, M.D.

Abstract
This article examines the definition of value in medical care for palliative care patients and describes an interdisciplinary Palliative Care Services Agreement, which is a framework for valued, financially sustainable palliative care at a 700-bed academic medical center. Quality standards drive team interdiciplinarity and also serve as metrics for financial support. The agreement defines staffing ratios necessary for sustainable team growth and represents a financial model that positions the field of palliative medicine competently among other medical specialties.

Integrating Palliative Care to Promote Earlier Conversations and to Increase the Skill and Comfort of Nonpalliative Care Clinicians: Lessons Learned From an Interventional Field Trial

Marlene K. Sorensen, MD, MPH, Jessica Vaughan, MA, Beth McLaughlin, MD, Carol Mahoney, APRN, A.C.M.H., Kurtis Puryear-Wilson, MD, and Mary Willwerth, MSN, RN, OC, NE-BC

Abstract
This article explores the use of palliative care in the clinical setting as a way to improve clinical outcomes and patient satisfaction. It is a growing field of practice and service that is expanding and becoming a larger part of patient care. This expansion is a way to improve the outcomes of patients and their families. The need for better quality of life and improved outcomes has led to the development of palliative care programs in hospitals and other healthcare settings. This study examines the impact of an interventional field trial on the delivery of palliative care services and how these services can be integrated into the daily practice of non-palliative care clinicians. The results of this study provide evidence that palliative care services can be successfully integrated into the daily practice of non-palliative care clinicians.
Organizational Advocacy

- What is your organizational sentiment?
- Mission, Vision, Goals – Know ‘em, align ‘em
  - For self
  - For group
  - For organization
- How easy/hard is it to get resources?
- Is your team indispensable?

Research

- Consuming
- Implementing
- Doing
Consuming Research

• Who feels up to date on the latest?
• Free and paid resources
  – PC-FACS
  – Fast Facts – PC-NOW
  – Social media
  – Journal clubs
  – State of the Science
• Share and discuss internally
Implementing Research

• Get reports and know your own data
• Take QI courses
  – AHRQ
  – AMA STEPPS Forward
  – Organizational resources
• Ask simple questions
• Test published research
• What quality measures are you testing?

Research

Consuming  Implementing  Doing
Doing Research

- Moving beyond QI
- Participate in a palliative care registry
  - Palliative Care Quality Network
  - Global Palliative Care Quality Alliance
  - Center to Advance Palliative Care
- Collaborate with non-palliative partners
  - Access to your patient population
- Find internal grants

Workforce

National  Regional  Local
National Workforce

- Professional Certification
- GME Funding
- Educational standards
- Exposure to palliative care for learners
We advocate for patient-focused, family-oriented care for people with advanced illness through education, clinical service and research.

Fig. 1. Ratio of hospice and palliative medicine physicians to older population. HPM, hospice and palliative medicine; N/A, not applicable.

Lupu, JPSM, 2018
Regional Workforce

- Geographic distribution
- Scope of practice
- Exposure to palliative care for learners
Local Workforce

- HPM Fellowships
- Non-physician training opportunities
- On-the-job training
- Exposure to palliative care for learners
- Geographic distribution
- Which professional helps most?

Find Your Action Point

- Advocacy
  - Social, Political, Organizational

- Research
  - Consuming, Implementing, Doing

- Workforce
  - National, Regional, Local
Summary

• You cannot do it all!
• What is your role? What can you do?
• What can you support?
  – Action, time, resources
• Have this conversation with others
• Commit to an action