Primary Care at the End of Life

Claire Ankuda MD MPH
Itinerary

• Trends in EOL care: defining the problem
• Why do we care about primary care involvement?
• What have I learned?
• Proposal for future directions/discussion
What is the problem?
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
Changes in EOL Care in the Last Decade

- Deaths in Acute Care Hospitals (%)
- ICU use in the last month of life (%)
- Hospice use at the time of death (%)
- Health care transitions in the last 90 days of life per decedent
- Healthcare transitions in the last 3 days of life (%)

Source: Teno et al 2014 JAMA
Why care about primary care’s role in palliative care?
Reason 1: There will never be enough specialists

Figure 1: Number of Persons 65+, 1900 to 2060 (numbers in millions)

Estimates of the U.S. Population, by Age, 1950 to 2050

PEW RESEARCH CENTER
Reason 2: PCPs may do better than specialists

The theory: PCPs assist with coordination, they know you well and can help define goals of care
Primary doctors are positioned to integrate palliative care over the lifecourse

Source: *Journal of the Royal Society of Medicine*, September 2001

http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1282181/
The only broad study of this in patients at the EOL

Table 3. Hospital Utilization$^5$ and ACSC$^{11}$ Admissions within Selected Patient Cohorts by Level of Prior Primary Care Use$^6$

<table>
<thead>
<tr>
<th>Number of Primary Care Visits</th>
<th>Non-SNF Users Hospital Days (95% CI) N=68,170</th>
<th>SNF Users Hospital Days (95% CI) N=10,186</th>
<th>Sickest Quartile Hospital Days (95% CI) N=19,589</th>
<th>CHF Admission Odds Ratio (95% CI) N=24,856</th>
<th>COPD Admission Odds Ratio (95% CI) N=20,161</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>15.4 (15.1,15.6)</td>
<td>14.5 (13.5,15.4)</td>
<td>22.7 (21.6, 23.9)$^4$</td>
<td>Reference</td>
<td>Reference</td>
</tr>
<tr>
<td>1–2</td>
<td>16.2 (15.9,16.5)$^4$</td>
<td>13.9 (13.0,14.8)</td>
<td>21.9 (20.8, 23.0)$^4$</td>
<td>1.00 (0.93,1.12)</td>
<td>0.96 (0.84,1.10)</td>
</tr>
<tr>
<td>3–5</td>
<td>15.7 (15.4,16.1)</td>
<td>13.8 (12.9,14.6)$^4$</td>
<td>21.1 (19.8, 22.4)$^4$</td>
<td>0.98 (0.89,1.08)</td>
<td>0.85 (0.74,0.98)$^a$</td>
</tr>
<tr>
<td>6–8</td>
<td>14.4 (13.9,14.9)$^4$</td>
<td>12.9 (11.9,13.9)$^4$</td>
<td>20.5 (19.3, 21.7)$^4$</td>
<td>0.88 (0.79,0.99)$^*$</td>
<td>0.75 (0.63,0.90)$^*$</td>
</tr>
<tr>
<td>≥9</td>
<td>13.8 (13.3,14.3)$^4$</td>
<td>11.6 (10.8,12.5)$^4$</td>
<td>19.5 (18.8, 20.3)$^4$</td>
<td>0.82 (0.74,0.92)$^*$</td>
<td>0.81 (0.68,0.97)$^*$</td>
</tr>
</tbody>
</table>

$^a$P<0.05, reference=0 primary-care visits  
$^b$P<0.01, reference=0 primary-care visits, no Skilled Nursing Facility (SNF) services  
$^c$P<0.01, reference=0 primary-care visits, lowest quartile comorbidity (least sick), after population was first stratified into four quartiles by comorbidity risk score  
$^d$Utilization measured during final 6 months of life, and adjusted for age, sex, race, Medicaid, nursing home use, comorbidity, geographic variation (hospital service area)  
$^{11}$ACSC, ambulatory care sensitive conditions: CHF, congestive heart failure; COPD, chronic obstructive lung disease. Admissions for ACSC measured during final 6 months of life and adjusted for age, sex, race, Medicaid, nursing home use, and comorbidity  
$^e$Primary-care visits measured during pre-period, months 18-7 before death
Reason 3: Let’s avoid system redundancy

“Palliative care is just family medicine on steroids.”

-- Ira Byock MD
IOM Recommendations for Palliative Care

• Care should be seamless, high-quality, patient-centered, family-oriented and consistently available around the clock
• Consider evolving physical, emotional, social, and spiritual needs of individuals as well as families and caregivers
• Include coordinated, efficient and interoperable information transfer across providers and settings
• Be consistent with patient goals, values and preferences
• Be competently delivered by professionals with appropriate expertise and training
Why is this familiar?
Defining the PCMH

1. Comprehensive Care
2. Patient-Centered
3. Coordinated Care
4. Accessible Services
5. Quality and Safety
One vision of primary care based palliative care – the Gold Standard Framework (GSF)

Summary of suggested three steps for earlier identification

**Step 1**
Ask the Surprise Question
Would you be surprised if the patient were to die in next months, weeks or days?

- **NO**
- **Don’t Know**
- **YES**

**Step 2**
Do they have General Indicators of Decline?

- **YES**
- **Don’t Know**
- **Reassess regularly**

**Step 3**
Do they have Specific Clinical Indicators?

- **YES**
- **NO**

Begin GSF Process

- **Identify** Include the patient on the GP’s GSF/QOF palliative care register or locality register if agreed. Discuss at team meeting.
- **Assess** Discuss this with patient and carers, assess needs and likely support and record advance care planning discussions.
- **Plan** Plan and provide proactive care to improve coordination and communication.
But before we propose stronger primary care models for palliative care

• We have to understand current primary care involvement

• We have to understand the barriers to greater involvement
  – Payment systems
  – Specialist-driven care
What I’ve learned
Figure 1. The Ratio of Primary Care to Specialist Visits in the Last Two Years of Life
Figure 2. Patterns of End of Life Care Across Hospital Referral Regions

Percent of Patients Seeing 10 or More MDs in the Last 6 Months of Life

Average Number of Days in the ICU in the Last 6 Months of Life

Percent of Deaths including ICU stay

Percent of Decedents Enrolled in Hospice

Dartmouth Atlas, 2010
Table 3. Adjusted Rates (95% Confidence Interval) of End of Life Outcomes According to Quartile of Primary Care Involvement in the Last 6 Months of Life

<table>
<thead>
<tr>
<th>Quartile of HRRs by Ratio of Primary Care to Specialist Visits in the Last 2 Years of Life</th>
<th>Lowest</th>
<th>2nd</th>
<th>3rd</th>
<th>Highest</th>
<th>p for quartiles</th>
<th>p for linear trend</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percent of deaths occurring in hospitals</td>
<td>23.84 (22.51-25.17)</td>
<td>24.00 (22.95-25.05)</td>
<td>24.35 (23.29-25.41)</td>
<td>24.46 (23.20-25.72)</td>
<td>0.57</td>
<td>0.97</td>
</tr>
<tr>
<td>Percent of decedents enrolled in hospice</td>
<td>51.54 (48.91-54.17)</td>
<td>48.09 (46.02-50.17)</td>
<td>46.97 (44.89-49.06)</td>
<td>43.71 (41.22-46.20)</td>
<td>0.00</td>
<td>0.00</td>
</tr>
<tr>
<td>Percent of patients seeing 10 or more physicians in their last 6 months of life</td>
<td>41.93 (40.33-43.54)</td>
<td>37.96 (36.70-39.22)</td>
<td>36.94 (35.67-38.21)</td>
<td>37.54 (36.02-39.06)</td>
<td>0.00</td>
<td>0.00</td>
</tr>
<tr>
<td>Percent of patients receiving ICU care during their final hospital admission</td>
<td>17.29 (16.43-18.16)</td>
<td>15.80 (15.12-16.49)</td>
<td>15.24 (14.55-15.92)</td>
<td>14.82 (14.00-15.64)</td>
<td>0.00</td>
<td>0.00</td>
</tr>
<tr>
<td>Hospital days in the last 6 months of life</td>
<td>9.69 (9.30-10.07)</td>
<td>9.06 (8.76-9.36)</td>
<td>9.04 (8.73-9.34)</td>
<td>9.15 (8.79-9.51)</td>
<td>0.08</td>
<td>0.11</td>
</tr>
<tr>
<td>ICU days in the last 6 months of life</td>
<td>4.37 (4.07-4.68)</td>
<td>3.61 (3.37-3.84)</td>
<td>2.99 (2.75-3.23)</td>
<td>2.92 (2.63-3.20)</td>
<td>0.00</td>
<td>0.00</td>
</tr>
<tr>
<td>Percent of cancer patients receiving life-sustaining therapy in the last month of life</td>
<td>9.55 (9.00-10.10)</td>
<td>8.56 (8.11-9.00)</td>
<td>8.29 (7.82-8.75)</td>
<td>8.73 (8.17-9.28)</td>
<td>0.08</td>
<td>0.41</td>
</tr>
<tr>
<td>Total Medicare spending/decedent in last two years of life (in 1,000s of USD)</td>
<td>69.43 (67.56-71.30)</td>
<td>66.80 (65.32-68.27)</td>
<td>63.81 (62.32-65.29)</td>
<td>65.20 (63.43-66.97)</td>
<td>0.01</td>
<td>0.00</td>
</tr>
</tbody>
</table>

Abbreviations: HRR= hospital referral region, ICU= intensive care unit, USD= United States Dollars, 2010.

1 Adjusted for the HRR percentage of population below the federal poverty level, percentage of Medicare beneficiaries reporting they are African American, average age of Medicare beneficiaries, average hierarchical condition category score of Medicare beneficiaries, percentage of HRR that is urban, obesity rate, and stroke rate of Medicare beneficiaries.

2 Comparing the 1st and 4th quartile of HRRs

3 Testing the ratio of primary care to specialist visits as a linear variable
Which FPs participate in non-clinic based palliative care?

• 7% of FPs routinely see patients in hospice
  – They are significantly more likely to be male, in the South vs the Northeast, in more rural regions, and in a PCMH
Which FPs participate in non-clinic based palliative care?

- 23% of FPs routinely see patients in nursing homes
  - They are more likely to be male, white as opposed to AA, non-Hispanic, practicing for longer, in more rural regions and in a PCMH
Which FPs participate in non-clinic based palliative care?

- 15% of FPs routinely make home visits
  - They are more likely to be white as opposed to AA or asian, more likely to have been practicing for 11+ years as opposed to 0-10, more likely to live in more rural regions, and more likely to be practicing in a PCMH or a PCMH-applicant clinic
Also: how FPs practice is very regional
Future directions
Specialist vs generalist care
Specific Questions

• On the patient level, what are the various outcomes for primary care vs specialist care?

• What exactly is primary care involvement?
  – Symptom management, home visits, goals of care discussions, coordination

• Do practice models in primary care affect EOL care?
  – RCT of clinics with an “advanced PCMH” model targeting chronically ill

• Do state policies that affect primary care affect the EOL trajectories of patients living there?
Specific research questions

• What would happen to spending and outcomes if we could finance a “social support” package along with medical care packages in the chronically ill elderly?

• How do we foster grassroots, community-based work to care for the dying?
Regional variation

Figure 2. Patterns of End of Life Care Across Hospital Referral Regions

- Percent of Patients Seeing 10 or More MDs in the Last 6 Months of Life
- Average Number of Days in the ICU in the Last 6 Months of Life
- Percent of Deaths including ICU stay
- Percent of Decedents Enrolled in Hospice

Dartmouth Atlas, 2010
What regions to explore

• Bordering regions with very different pictures of PCP engagement
• High PCP engagement despite high care intensity (lots of specialists and ICU beds)
• Regions with patterns that stand out (hospice in the SE and Texas, PCPs in New England)
Focusing on hospice

Silveira et al. 2011
Little regulation, and regulation matters

Carlson, 2008

Fig. 1. Differences in the percentage of patients receiving each hospice service in certified and non-certified hospices, by hospice ownership. Note: Only services for which certification differences significantly \((P < 0.05)\) differed for patients enrolled with for-profit compared with nonprofit hospices are shown.

Carlson, 2008
Thanks to all!