Having the Conversation Nobody Wants to Have Benefits Everybody

Value-Based End-of-Life Care

Speakers:
Sukey Barnum, Principal, HMA
Suzanne Mitchell, MD, Principal, HMA
Laurie Lockert, Senior Consultant, HMA

Moderator:
Carl Mercurio, HMA Information Services

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Value Based End-of-Life Care and Planning

PROBLEM STATEMENT
The way people die has, in large part, changed significantly over time; and our systems for dealing with dying and death have not evolved to respond to new and forthcoming realities and to result in quality end of life planning and care.
We Die Older

Sources: Census.gov, CDC.gov, Data360.org; *Projected
## We Die More Slowly

<table>
<thead>
<tr>
<th></th>
<th>1900</th>
<th>2000</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age at Death</strong></td>
<td>46</td>
<td>78</td>
</tr>
<tr>
<td><strong>Top Causes of Death</strong></td>
<td>Infection Accident Childbirth</td>
<td>Cancer Organ System Failure Stroke Dementia</td>
</tr>
<tr>
<td><strong>Disability</strong></td>
<td>Not much</td>
<td>Average 2-4 years before death</td>
</tr>
<tr>
<td><strong>Financing</strong></td>
<td>Private, Modest</td>
<td>Public, Substantial</td>
</tr>
</tbody>
</table>

**Source:** J. Lynn, 2015
Systems

- Healthcare payers pay for curative care
- Healthcare education focuses on curative care
  - Survey of 122 medical schools and 34 nursing schools to obtain information regarding coursework training in the areas of palliative, emotional, and spiritual care to the dying (Cowgill and Cowgill, 2013)
    - 8 medical schools and 0 nursing schools had mandatory course work
    - 16 medical school offered elective course work
- We are culturally focused on curative care
Discomfort and Fear: EOL Conversations

**Individuals**
- Difficulty accepting diagnosis
- Fear about care that will or won’t be provided
- Worry about family members’ burden or perspective

**Families**
- Lack of clear decision tree
- Fear of guilt
- Lack of knowledge/understanding of individual’s preference

**Providers**
- Reluctant to deliver bad news
- Admission of defeat
- Change in relationship with individual
- Fear of offense
Barriers to Conducting Effective EOL Conversations

• Language and medical interpretation issues
• Patient/family religious and spiritual beliefs about death and dying
• Doctor’s ignorance of patients’ cultural beliefs, values, and practices
• Cultural differences in truth handling and decision making
• Patient/family’s limited health literacy
• Patient/family’s mistrust of doctors and the healthcare system

Value Based End-of-Life Care and Planning

SYSTEM AND CULTURAL CHANGE
Medicare and EOL

- January 1, 2016, Medicare begins paying for end-of-life discussions
- Medicare Care Choices Model
  “…to receive hospice-like support services… while concurrently receiving...curative care…”
Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life

Released: September 17, 2014

REPORT AT A GLANCE

- The Conversation (HTML)
- Introductory Slides (HTML)
- Organizational Commitment Statements (HTML)
- Report Brief (PDF, HTML)
- Stakeholder Webinar Recording (HTML)
- Stakeholder Webinar Slides (HTML)
- Key Findings and Recommendations (PDF)
- Core Components of Quality End-of-Life Care (PDF)
- Infographic (PDF)
- Palliative Care Graphic (PDF, HTML)
- Palliative Care Graphic (Spanish) (PDF, HTML)
- Palliative Care Graphic (Portuguese) (PDF, HTML)
'Right to Try' Legislation Tracker

Posted 24 June 2015
By Alexander Gaffney, RAC

Since early 2014, more than 20 states have introduced so-called "Right to Try" bills in the hopes of allowing terminally ill patients to access experimental—and potentially life-saving—treatments more easily. These bills are modeled off a federal policy known as "Compassionate Use," but contain several key changes meant to make it faster and easier for patients to obtain experimental therapies.

This Right to Try Legislation Tracker is meant to be a resource for regulatory professionals and patients to keep track of legislation as it moves through various state legislative bodies.

Last updated 25 June 2015: Legislation awaiting Governor's signature in North Carolina. Fixed error indicating Maine had passed a RTT law (it has not).

States With Right to Try Laws

<table>
<thead>
<tr>
<th>State</th>
<th>Link to Legislation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alabama</td>
<td>Text of Legislation</td>
</tr>
<tr>
<td>Arizona</td>
<td>Ballot Measure</td>
</tr>
<tr>
<td>Arkansas</td>
<td>Text of Legislation</td>
</tr>
<tr>
<td>Colorado</td>
<td>Text of Legislation</td>
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<tr>
<td>Florida</td>
<td>Text of Legislation</td>
</tr>
<tr>
<td>Indiana</td>
<td>Text of Legislation</td>
</tr>
</tbody>
</table>
November 19, 2015, is our first ever Day of Gratitude, in honor of Brittany Maynard’s birthday. Because Brittany shared her story and touched the lives of millions of people, more than half of the states and the District of Columbia introduced aid in dying legislation in 2015.
Diane Rehm On Living—and Dying—with Dignity
“If your problem is fixable, we know just what to do. But if it’s not? The fact that we have had no adequate answers to this question is troubling and has caused callousness, inhumanity and extraordinary suffering.”
Welcome to Death Cafe

At a Death Cafe people drink tea, eat cake and discuss death. Our aim is to increase awareness of death to help people make the most of their (finite) lives.

Read more
What is End of Life Care?
Uncertainty in Late Stage Illness
Palliative Care vs Hospice

• **Palliative care** focuses on the best-possible QoL based on patient/family needs and goals, independent of prognosis or care setting.
  • Addresses symptom burden, complex medical decision making, mobilize practical aid.

• **Hospice** provides palliative care in the **last six months** of a terminal illness & bereavement.
  • When hospice care is chosen, a beneficiary is no longer eligible to receive curative care.

• Both are interdisciplinary.
Medical Care In Late Stage and Serious Illness
Concurrent Care = Palliative + Curative
Value Based End-of-Life Care

THE BUSINESS CASE
Palliative care programs increase value by both improving quality and reducing costs of care.

Value Proposition for Palliative Care

**Quality**
- Be home
- Family support, care coordination, home care
- Less symptom burden
- Higher satisfaction
- May prolong life

**Cost**
- Fewer acute admissions
- More hospice referrals
- Direct admissions to the palliative care service
- Avoid non-beneficial or harmful services and procedures
What is Hospice Benefit?

- Formalized as a Medicare benefit in 1982. Covered by both Medicare and Medicaid.

- Only 47% of Medicare beneficiaries use hospice care and only for a short time.

- Low enrollment in part due to reluctance to forgo curative care.
Business Case: Palliative Care

- Average per-patient per-admission net cost saved by hospital palliative care consultation is $2,659
- Palliative care programs should serve ~6% discharges
- In 2009, PC programs reach ~1.5% discharges with estimated savings of $1.2B/year at 1,500 U.S. hospitals

Saving could reach ~ $4 Billion/year if capacity were expanded

(Morrison, Meier, and Carlson 2011; Morrison et al. 2008; Siu et al. 2009).
Business Case: Hospice care

- An estimated $2,300 is saved per hospice patient, compared with similar patients not receiving hospice services

\[1.5M \text{ hospice patients served} \times \$2,300 = \$3.5\text{Bil/yr}\]

(Carlson 2010) (Taylor 2009; Taylor 2007)
Barriers to Palliative Care & Hospice

• Variability in access
• Inadequate workforce
• Insurance barriers
• Lack of public knowledge of, and demand for, the benefits of palliative care and hospice
• Lack of public trust creates reluctance to engage in advance care planning
Opportunities for Value-based EOL Care

ACA law allows integration of palliative care and hospice programs in (ACOs), (PCMHs) and the bundling of payments for a single episode of health care.
Concurrent Care Model

• Medicare Care Choices Program: the option to receive supportive care services typically provided by hospice, while continuing to receive curative services.
Effective Advanced Care Planning

• Relationship-centered decision making for EOL Care
  – Engage a healthcare proxy
  – Assess past experiences
  – Meet people where they’re at in acceptance
  – Don’t force a DNR
  – Revisit decisions on care whenever needed
  – Avoid abandonment
The Conversation: Advance Care Planning

Assess

Advance Care Planning Discussion

How?
- Opportunistic informal conversations
- Formalised systematic

What?
- What matters to you?
- What do you wish to happen?
- What do you do not want to happen?

Who?
- Named spokesperson (informal)
  Can tell those who act in best interests what sort of person you are
- Lasting Power of Attorney (formal)
  Can make legal decisions regarding your health

Where?
- Preferred Place of Care
- Carer’s Preferred Place of Care

Other?
- Special instructions: Organ/tissue donation
Using trauma-informed practices to have the conversation with your patients

A CASE STUDY: ANN
Ann’s EHR Problem List

- Alcohol dependence in remission
- COPD
- Lung cancer Stage III
- Cannabis abuse
- Self-injurious behavior
- Antisocial personality disorder
- Noncompliance with medication treatment due to overuse of medication
- Ankle fracture
- Depressive disorder

- PTSD
- GAD (Generalized Anxiety Disorder)
- Bipolar disease, depressed
- Vaccine refused by patient
- Hand fracture
- Broken wrist
- Drug-seeking behavior
- Benzodiazepine abuse, continuous
Traumatic events

- Physical assault
- Sexual abuse
- Emotional or psychological abuse
- Neglect/abandonment
- Domestic violence
- Witnessing abuse/violence
- War/genocide

- Accidents
- Natural or man-made disasters
- Dangerous environment
- Witness or experience street violence
- Poverty
- Homelessness
- Historical trauma and current oppression
Impact of Trauma

• Emotional Reactions
  – Feelings-regulation
  – Alteration in consciousness
  – Hypervigilance

• Psychological and Cognitive Reactions
  – Concentration impaired, slowed thinking, difficulty with decisions, blame

• Behavioral or physical
  – Pain, sleep, illness, substance use

• Beliefs
  – Changes your sense of self, others, world
  – Relational disturbance
Trauma Informed Care

• A program, organization, or system that is trauma-informed:
  – Realizes the widespread impact of trauma and understands potential paths for recovery;
  – Recognizes the signs and symptoms of trauma in clients, families, staff, and other involved with the system;
  – Responds by fully integrating knowledge about trauma into policies, procedures, and practices; and
  – Seeks to actively resist re-traumatization

(SAMHSA, 2014)
Coming in to Talk with Ann

• Who should have the conversation with patients?
• Quiet, calm, unhurried time to talk
• An invitation to talk:
  “Ann, I understand you just had a difficult conversation with your doctor during your recent hospitalization. Would it be ok to talk about it?”
The Conversation with Ann

• Use short explanations; check for understanding and questions
• Give a person time to think... but long silences are not helpful
• Use non medical language
• Leave the door open for future conversations
• Trust that people will lead you and provide information
We Want to Engage People, Not Re-traumatize Them

• Develop a script for yourself. Carry it in your pocket and use it.
  – “Help me understand what the medical team told you.”
  – “What do you understand about your situation?”
  – “What is most important to you?”
  – “What would help you the most to live better?”

• Listen. Provide information. Keep explanations simple and short. Check for understanding.