C-TAC: The Coalition to Transform Advanced Care

www.thectac.org
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David E. Longnecker, MD
C-TAC’s vision for a better future...

All Americans with advanced illness, especially the sickest and most vulnerable, will receive comprehensive, high-quality, person- and family-centered care that is consistent with their goals and values and honors their dignity.
Advanced illness is that stage in the progression of one or more conditions when general health and functioning decline, curative treatments become less effective and overall quality of life increasingly becomes the focus of care. This may happen in the course of any disease and at any age but is more common in older populations.

Advanced illness care encompasses a broad range of social and clinical services, including palliative care and hospice care, but it is not synonymous with either, nor is it end-of-life care only. Specialists may be engaged in aspects of advanced illness care, but typically it is led by primary care, delivered by interprofessional teams, bolstered by community engagement and guided by the personal preference, not medical protocol only. As a result, it is often home-based.
The advanced illness care continuum

Delivered based on an informed and shared decision-making process involving evidence, clinicians’ expertise, and patients’/families’ wishes and goals.

Delivered on a continuum* at the right time and in the right setting as determined by patients and their families with input from clinicians, families/caregivers, and spiritual advisors.

*Care Continuum:

- **Advance Directive**
  - **Phase 1**: Healthy or with reversible illness
  - **Phase 2**: Early onset, chronic conditions
  - **Phase 3**: Progressive, frequent complications
  - **Phase 4**: Hospice eligible

- **Advance Care Planning**
  - **Chronic and Curative Care**
  - **Palliative Care**
  - **Hospice**

Disease Progression
Why advanced illness care matters…

- 11,000 Americans turn 65 every day
- 65+ group will double to 72m in two decades
- 25% of seniors lose all their assets due to costs of advanced illness care
- 41% lose all of their assets except housing
- People want care that enhances quality of life, keeps them at home, and keeps them from being a burden to their family
## The Big Gap…

<table>
<thead>
<tr>
<th>What People Want</th>
<th>What They Get</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Be at home with family, friends</td>
<td>Recycled through the hospital</td>
</tr>
<tr>
<td>2. Have pain managed</td>
<td>Often inadequate, ineffective or inappropriate treatment</td>
</tr>
<tr>
<td>3. Have spiritual and emotional needs addressed</td>
<td>Often die in hospital, in pain and isolation</td>
</tr>
<tr>
<td>4. Avoid impoverishing families</td>
<td>Great cost to families and the nation.</td>
</tr>
</tbody>
</table>
Health Spending Is Very Highly Concentrated Among the Highest Spenders

Top 1% of spenders account for 23% of spending

Top 5% of spenders account for 50% of spending

NIHIM Foundation analysis of data from the 2012 Medical Expenditure Panel Survey.
What does successful advanced illness care look like?

- **Improved Shared Outcomes**
  - e.g., person-centered care; reduced unwanted hospitalizations

- **Patient/Family Decision-Making**
  - with coordinated input from clinicians and trusted advisors

- **Clinical Interventions**
  - e.g., symptom management

- **Community and Social Support**
  - e.g., respite care for caregiver

- **Policy Advocacy**

- **Public Engagement**

(C-TAC logo and text)
Community Engagement

- PCORI Conference Award (2016-2018)
  - Goal: Create national network of prepare sites for multi-site research/fact finding (2016-2018)
  - Principal Investigators:
    - Rev. Tyrone Pitts, C-TAC; and
    - Rebecca Aslakson, MD, Johns Hopkins
  - National Leadership Conference (June 2-3, 2016)
Lessons Learned: Listening

• There are latent, underused resources that are not well linked between communities and providers

• Systematic linkage of community and clinical models hold great promise for both provider and person outcomes

• African-Americans identified their faith-based organizations and leaders as trusted resources

• Faith-based personnel need training & partners to serve as links between health systems and community
Lessons Learned: Listening to the Community

• C-TAC conducted listening sessions in multiple regions:
  – Washington, DC; Detroit, MI; New York, NY; Oakland, CA; San Diego, CA; Portland, OR; Providence, RI.

• Participants included (oversampled for American Africans):
  – Places of worship, health-systems, patients, family caregivers, and Workgroups (Clinical, etc.) of C-TAC.

Key Concern: Even if you have a seat at the table, do you have a “say” in the care for your community, as part of the health system?

*Pitts, Tyrone (July 2015): Presentation at the IOM Roundtable on Palliative Care and Health Literacy
What does successful advanced illness care look like?

- **Improved Shared Outcomes** (e.g., person-centered care; reduced unwanted hospitalizations)
- **Clinical Interventions** (e.g., symptom management)
- **Patient/Family Decision-Making** with coordinated input from clinicians and trusted advisors
- **Community and Social Support** (e.g., respite care for caregiver)

Policy Advocacy

Public Engagement
Sutter Health AIM Program
(Principally Team-Based/Home-Based)

Care Model

- Re-engineered at home, office & hospitals
- Interprofessional team-based care
- Care coordination, advanced care planning

Results

- 60% reduction in hospitalizations
- 22% reduction in ED visits
- 80% reduction in ICU days
- >95% patient satisfaction
- >90% physician satisfaction
Aetna Compassionate Care Program
(Principally telephonic case management)

- Favorable Medicare Advantage impact aligning patient goals with outcomes (2012)
  - 82% of engaged decedents choose hospice
  - 82% reduction in acute inpatient days
  - 77% reduction in emergency room visits
  - 86% reduction in intensive care unit days
  - $12,924 mean savings per member engaged

<table>
<thead>
<tr>
<th>Not in ACCP</th>
<th>Period Prior to Death</th>
<th>In ACCP</th>
<th>Impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>$14,528</td>
<td>1 Month</td>
<td>$8,609</td>
<td>$5,919</td>
</tr>
<tr>
<td>$10,974</td>
<td>2 Months</td>
<td>$6,652</td>
<td>$4,323</td>
</tr>
<tr>
<td>$8,990</td>
<td>3 Months</td>
<td>$6,308</td>
<td>$2,682</td>
</tr>
<tr>
<td>$7,602</td>
<td>4 Months</td>
<td>$5,917</td>
<td>$1,685</td>
</tr>
<tr>
<td>$6,569</td>
<td>5 Months</td>
<td>$5,518</td>
<td>$1,052</td>
</tr>
<tr>
<td>$5,803</td>
<td>6 Months</td>
<td>$5,266</td>
<td>$537</td>
</tr>
</tbody>
</table>
What are some themes across these emerging models?

1. Builds on existing resources in Community
   - Social service agencies (e.g., senior centers)
   - Faith-based organizations
   - Community Health Clinics
   - Advocacy organizations

2. Links Community and Clinical Resources
   - Community-Based Palliative Care
   - Home Care
   - Complex Care Management
   - Hospice

3. Delivered by interdisciplinary, team-based care model
   - **Community:**
     - community health workers, community pharmacists, clergy, volunteers
   - **Clinical:**
     - Nurse (RN, LPN), social workers, physicians, pharmacists; chaplains
What does successful *advanced illness care* look like?

- **Improved Shared Outcomes** (e.g., person-centered care; reduced unwanted hospitalizations)
- **Clinical Interventions** (e.g., symptom management)
- **Patient/Family Decision-Making** with coordinated input from clinicians and trusted advisors
- **Community and Social Support** (e.g., respite care for caregiver)

*Policy Advocacy* ↔ *Public Engagement*
Respecting Choices
Mission and Vision

Mission:
We guide organizations and communities worldwide to effectively implement and sustain evidence-based systems that provide person-centered care

Vision:
To transform healthcare culture by integrating and disseminating best practices to achieve person-centered care
Respecting Choices
An Advanced Care Planning System

• Implemented in more than 130 health systems nationally and internationally

• Evidence-based approaches that emphasize systematic processes, ready availability and sustainability (not “one and done”)
What does successful **MOVEMENT** advanced illness care look like?

- **Improved Shared Outcomes** (e.g., person-centered care; reduced unwanted hospitalizations)
- **Patient/Family Decision-Making** with coordinated input from clinicians and trusted advisors
- **Clinical Interventions** (e.g., symptom management)
- **Community and Social Support** (e.g., respite care for caregiver)

**Policy Advocacy**

**Public Engagement**
Building a Movement in Advanced Illness Care

Key Components of Collective Impact*

- Common Agenda
- Shared Measures
- Mutually Reinforcing Activities
- Continuous Communication
- Backbone Support

*Stanford Social Innovation Review 2011
Person-centered Preferences to Guide Advanced Illness Care

- Purpose and Connection
- Physical Comfort
- Emotional and Psychological Well-Being
- Family and Caregiver Support
- Financial Security
- Peaceful Death and Dying

THE NORTH STAR: INDIVIDUAL PREFERENCES

BACKUP SLIDES

Fig. 1. All-cause mortality, ages 45–54 for US White non-Hispanics (USW), US Hispanics (USH), and six comparison countries: France (FRA), Germany (GER), the United Kingdom (UK), Canada (CAN), Australia (AUS), and Sweden (SWE).

Fig. 2. Mortality by cause, white non-Hispanics ages 45–54.