

POLICY AND POLITICS OF ADVANCED ILLNESS AND END-OF-LIFE CARE:
CHALLENGES AND OPPORTUNITIES

LONG-TERM CARE DISCUSSION GROUP
FEBRUARY 21, 2018

Andrew MacPherson

Principal, Healthsperien LLC

Senior Policy Advisor, Coalition to Transform Advanced Care (C-TAC)

Washington, D.C.



What is C-TAC?

The Coalition to Transform Advanced Care (C-TAC) is a nonpartisan, not-for-profit alliance of over 140 national healthcare stakeholders dedicated to the idea that all Americans with advanced illness, receive comprehensive, high-quality, person-centered care that is consistent with their goals and values, and honors their dignity.



What is Advanced Illness?

Advanced illness is defined as one or more conditions becoming serious enough that general health and functioning begin to decline, curative treatment loses its effectiveness, and care becomes increasingly oriented towards comfort — this process extends to the end of life.



OUR ULTIMATE QUESTION (AND OBJECTIVE)

How do we redesign our health care system to be fully responsive to one's goals, values, and wishes – especially at the end-of-life?

THE PROBLEM: “THE BIG GAP”

What People Want

1. Be at home with family, friends
2. Have pain managed
3. Have spiritual needs addressed
4. Avoid impoverishing families/being a burden

What They Get

Recycled through the hospital

Often unwanted, ineffective treatment

Often die in hospital, in pain and isolation

At great cost to families and the nation.

THE PROBLEM: THE “CONVERSATION” AND PHYSICIAN TRAINING

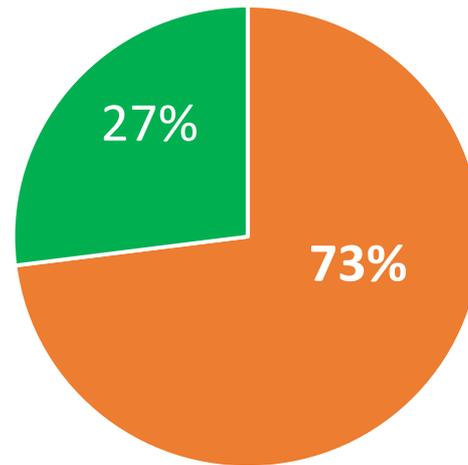
- A recent study show that approximately **42% of individuals** have had discussions on end-of-life issues.
- Yet **only 23%** put their care directives in writing and/or legal/medical (aka POLST) documentation.
- And **a full 90%** said that they physicians never asked about this issue.

Source: John H. Hartford Foundation

Not for copy or distribution

THE PROBLEM: AMERICANS HIGHLY CONCERNED ABOUT TREATMENT OPTIONS

How concerned are you about not having adequate treatment options at the end-of-life?



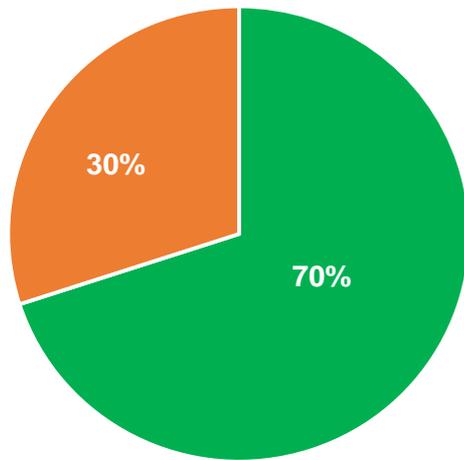
■ Concerned ■ Not Concerned

Source: Cambia Health, 2014

Not for copy or distribution

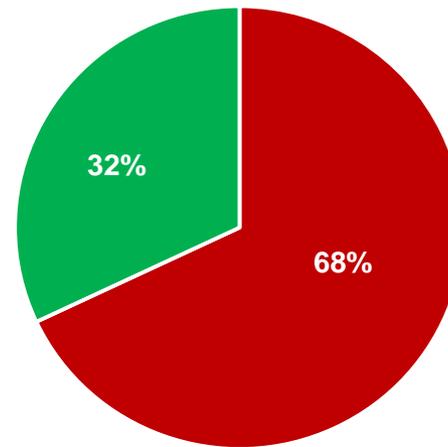
THE PROBLEM: WHERE DO INDIVIDUALS WISH TO DIE? AND WHERE DO THEY ACTUALLY DIE?

Where They Wish to Die



■ Home ■ Other/No Pref

Where They ACTUALLY Die



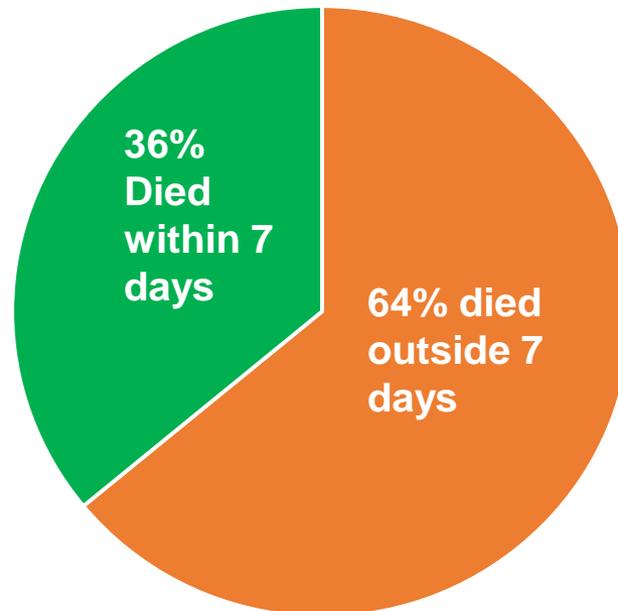
■ Other/No Pref ■ Home

Source: California Health Care Foundation, 2016

Not for copy or distribution

THE PROBLEM: HOSPICE SHORT LENGTH OF STAY

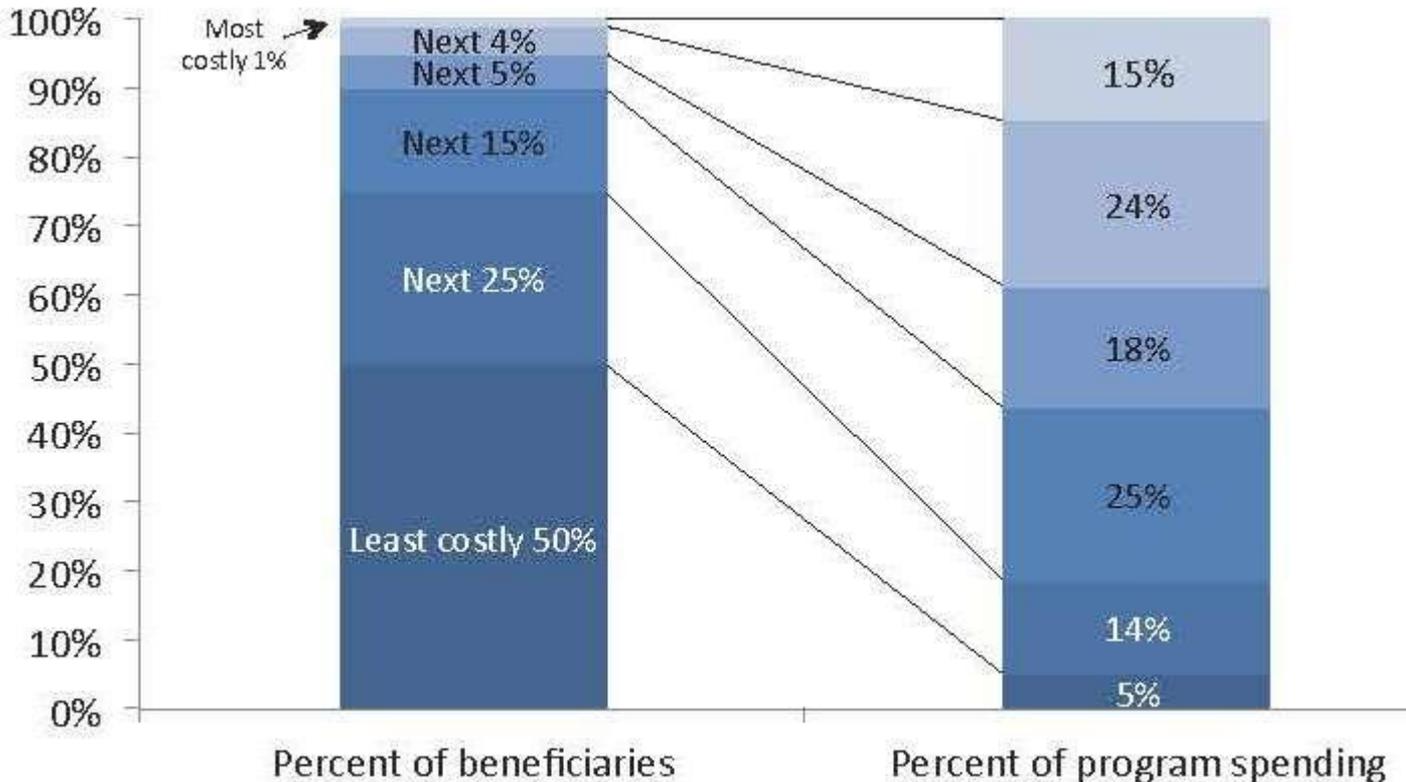
Despite Growing Average Length of Stay (25% increase over last 5 years), Short Stays Remain Very Concerning



Source: NHPCO, 2015

Not for copy or distribution

THE (MOST OBVIOUS) PROBLEM: COST IMPLICATIONS



Source: American Academy of Actuaries

C-TAC Policy & Advocacy

C-TAC, along with our members and partners, pursues a comprehensive policy agenda at both state and federal levels focused on delivery system reform, preference driven care, caregiver and consumer support, and professional engagement involving both legislative and regulatory strategies.



C-TAC Policy Priorities

C-TAC's agenda addresses the barriers to better advanced illness care:

- Promoting **person-centered care coordination** in advanced illness
- Supporting **payment structures for innovative models**
- Establishing **best practice based care**
- Identifying **comprehensive quality measures**
- Ensuring impact and accessibility of **advance directives**
- Increasing availability of resources for **family caregivers**
- Expanding the **advanced care workforce**

Our primary goal is to establish a Medicare advanced care demonstration through CMS. Payment is the number one barrier in providing services to people with advanced illness. This shift in how we pay for healthcare is a part of the national shift from quantity to quality



C-TAC Supported Legislation

- *The Patient Choice and Quality Care Act of 2017 (S.1334/H.R.2797)*
- *The Compassionate Care Act of 2017*
- *The Removing Barriers to Person-Centered Care Act of 2017*
- *Creating High-Quality Results and Outcomes Necessary to Improve Chronic (CHRONIC) Care Act (S.870) (Enacted)*
- *Independence at Home Act of 2017 (S. 464)*
- *Medicare Choices Empowerment and Protection Act of 2017 (H.R. 3181)*
- *Medicare Patient Access to Hospice Act of 2017 (H.R. 1284)*
- *Palliative Care and Hospice Education and Training (PCHETA) Act (H.R. 1676)*
- *Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act (H.R. 3759) (Enacted)*
- *Rural Access to Hospice Act (S. 980)*

Progress: *Creating High-Quality Results and Outcomes Necessary to Improve Chronic (CHRONIC) Care Act (S.870)*

Who?

Sens. Hatch [R-UT] and Wyden [D-OR] and **every** member of the Senate Finance Committee.

What?

- Extends Independence at Home demonstration by 2 years
- **Includes GAO study on “longitudinal care planning”**
- Permanently authorizes SNPs
- Expands testing of MA Value-Based Insurance Design test model.
- Allows MA to provide additional telehealth benefits to enrollees and, to chronically ill enrollees, certain supplemental health care benefits.
- Allows prospective, voluntary assignment of Medicare fee-for-service beneficiaries to accountable care organizations (ACOs), and
- Allows ACOs to operate beneficiary incentive programs.

PROGRESS: BIPARTISAN PUSH FOR ADVANCED ILLNESS CARE DEMONSTRATION & QUALITY MEASURE DEVELOPMENT

Congress of the United States
Washington, DC 20515

February 9, 2018

Alex Azar
Secretary

Department of Health and Human Services
200 Independence Avenue S.W.
Washington, D.C. 20500

Seema Verma, MPH
Administrator
Centers for Medicare and Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244

Dear Secretary Azar and Administrator Verma,

We appreciate your leadership in considering innovative models for quality, patient-centered care. Last year, we introduced the *Patient Choice and Quality Care Act* (H.R. 2797/S. 1334), which addresses a number of issues around quality care for individuals with serious, chronic progressive, or advanced illness. While our legislation provides new authority to address a number of important issues, we believe that the Centers for Medicare & Medicaid Services (CMS) already has the statutory authority to tackle some of the most urgent provisions in the legislation: the development of a patient-centered advanced illness care management model that supports individuals with serious and advanced illness, the development of measures to assess the quality of care for seriously ill individuals across the continuum and activities to support families and providers facing difficult health care decisions.

Testing Patient-Centered Care Models

Recent data show that Americans are living longer with significant changes in causes of sudden illnesses like pneumonia or unintentional injuries are no longer leading causes of death for a majority of Americans die from chronic conditions like heart disease, cancer, or dementia. While finding treatment options for chronic conditions is a priority, it is equally important to ensure that the majority of Americans die from chronic conditions like heart disease, cancer, or dementia. While finding treatment options for chronic conditions is a priority, it is equally important to ensure that the majority of Americans die from chronic conditions like heart disease, cancer, or dementia.

While finding treatment options for chronic conditions is a priority, it is equally important to ensure that the majority of Americans die from chronic conditions like heart disease, cancer, or dementia.

The *Patient Choice and Quality Care Act* takes the lessons learned from the demonstration of patient-centered care models that coordinate care for those with serious and advanced illness. Specifically, the legislation calls for the development of a patient-centered advanced illness care management model that supports individuals with serious and advanced illness. While our legislation provides new authority to address a number of important issues, we believe that the Centers for Medicare & Medicaid Services (CMS) already has the statutory authority to tackle some of the most urgent provisions in the legislation: the development of a patient-centered advanced illness care management model that supports individuals with serious and advanced illness, the development of measures to assess the quality of care for seriously ill individuals across the continuum and activities to support families and providers facing difficult health care decisions.

PRINTED ON RECYCLED PAPER

As indicated above, we believe that CMS has the authority to test this model of care under section 1115A of the Social Security Act and we urge the Secretary to direct staff to begin the process of adopting this model based on proposals already submitted to the Physician-Focused Payment Model Technical Advisory Committee (PTAC).

Measure Development under Section 1848(s)(6) of the Social Security Act
Better quality measures are necessary to assess the innovative care models under development, and to address the palliative and end-of-life care needs of people with serious, chronic progressive or advanced illness. Fixing this gap is critical to engaging providers, systems and insurers in supporting improvement for this population. The *Patient Choice and Quality Care Act* facilitates the development of such quality measures by increasing coordination and alignment between the public and private sector through measures that include a review of current measure concepts and preferred practices in end-of-life care.

CMS currently has the authority to advance these efforts through section 1848(s)(6) of the Social Security Act. The Department of Health and Human Services has the opportunity under its current authority and funding to help individuals with serious, chronic progressive, or advanced illness plan for their care and to make sure their choices are honored. Developing new quality metrics will allow individuals, providers, and policymakers identify models that honor patient choice and provide high-quality care.

Decision Support

Finally, our legislation would provide grants to develop decision-support tools that would empower patients to ensure their providers and caretakers are fully informed at every stage of their illness. As CMS considers strategies to strengthen beneficiary engagement, we encourage you to expand the Beneficiary Engagement and Incentives (BEI) Model to include advanced illness management.

We urge you to take administrative action to address these issues that are of significant concern not only to us but to the community of clinicians and patients concerned with the care of Medicare beneficiaries with serious, chronic progressive or advanced illness.

Again, we appreciate your ongoing efforts to improve the quality and delivery of care through payment models and quality measures and look forward to your response.

Sincerely,



Senator Johnny Isakson



Representative Phil Roe



Senator Mark Warner



Representative Earl Blumenauer

Encouraging Words From Secretary Azar

Senate Finance Committee Hearing on the Nomination of Sec. Azar:

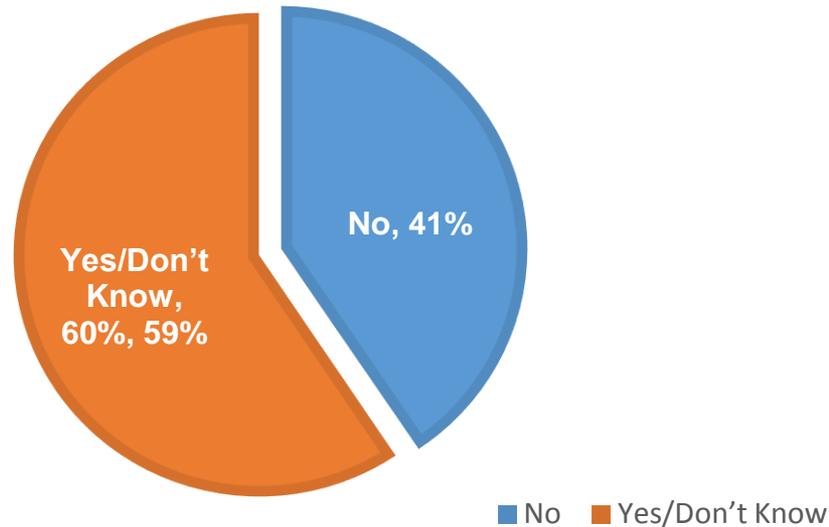
Senator Warner: An issue that Senator Isakson and I have been working on for a long time is advance care planning and end-of-life issues, and CMS obviously made a major step forward a few years back where they went ahead and put a coding in for that consult. I would just like to get you on the record in terms of [...] recognizing we don't want to limit anyone's choices, but we want to honor and respect people's choices about care planning or end of life issues.



HHS Nominee Azar: I think it's a very important part of all of our personal care management in life as we think about our life and our health care and our family members that we engage in that kind of thoughtful, directive planning of what do we desire. As you said, it's not about imposing any one's views on someone else it's actually about ensuring systems respect that individual's choices, and enabling that is very important for us.

YET, SERIOUS CHALLENGES REMAIN...

Question: *Does the Affordable Care Act allow a government panel to make decisions about end-of-life care for people on Medicare?*



Source: Kaiser Family Foundation

THANK YOU

ANDREW MACPHERSON

Senior Policy Advisor
Coalition to Transform Advanced Care (C-TAC)

Principal
Healthsperien, LLC

Andrew@healthsperien.com

C-TAC
COALITION TO TRANSFORM
ADVANCED CARE

