PERSON-CENTERED ADVANCED ILLNESS CARE ACROSS THE CONTINUUM

C-TAC
COALITION TO TRANSFORM ADVANCED CARE

AMERICANS INCREASINGLY SUFFER FROM ADVANCED ILLNESS.

While there is a lot of talk about the concept of "patient-centered care," the reality is that patients are not at the center of the current healthcare system. New care delivery and payment models, promoted by healthcare reform, focus on better care coordination and integration, but few include the elements that most people with advanced illness say are important, their families/caregivers, faith and other communities, and social services. This paper proposes the Coalition to Transform Advanced Care's (C-TAC) Advanced Care Model (ACM) as a pathway or framework for stakeholders - including healthcare providers, plans, and community-based organizations - as they wade through the plethora of new practices, policy options, and payment models for addressing advanced illness in a more holistic and patient-centered approach. It will also review Community Action Models, which when combined with the ACM, could extend the care support network well beyond the traditional healthcare system.

WHY THE TIME IS RIGHT

By 2030, 9 million Americans will be over the age of 85 and many will experience substantial disability and chronic conditions associated with older age.[i] Many will face *advanced illness,* which C-TAC defines as "when one or more conditions become serious enough that general health and functioning begin to decline, treatment may no longer lead to preferred outcomes, and care oriented toward comfort may take precedence over attempts to cure–a process that extends to the end of life."

C-TAC's goal is that all Americans living with advanced illness receive the care that honors their dignity and respects their values and preferences. There are many challenges to care delivery: The majority of Americans do not know or understand the meaning of palliative care; disparities in access to care and pain management continue to grow among minority populations; and overuse of services and mismanagement of medication is prevalent. These challenges are well documented in the Institute of Medicine's *Dying in America Report* (2014).[i] Achieving C-TAC's goal will take significant changes in public and professional education, care delivery processes, and public policy.

The good news is that change is underway. Evidence-based care models like Sutter Health's *Advanced Illness Management* (AIM), Aetna's *Compassionate Care,* Home-Based Primary Care through the Medicare Demonstration, *Independence at Home*, and Program of All-inclusive Care for the Elderly (PACE), and others, demonstrated greater patient satisfaction, higher quality and lower costs of care than the status quo.[iii] The Centers for Medicare and Medicaid (CMS) set new goals to shift to value-based payment models, bipartisan policy options to advance these practices are emerging, and people living with advanced illness are speaking out as advocates for change.[iv]

ACM—COMMON ELEMENTS

People suffering from advanced illness often fall through the cracks between the current care delivery programs available and provider groups. While there is a focus on moving care services out of traditional settings, such as hospitals, there is little infrastructure among community-based institutions, or informal caregivers, that facilitates the "handoff" of patient care. In many cases, family caregivers are now performing fairly complex medical tasks with little to no formal training.[v] Like

patients under disease management, people with advanced illness could also have multiple chronic conditions however, in most cases their decline in health and function is more pronounced, and is often irreversible. Many of these people are not yet eligible for hospice, and those who do qualify might be reluctant to enroll, or in some cases, their providers may be unwilling to refer them.

The ACM Framework is built on the successful efforts of those like, Sutter Health's *Advanced Illness Management (AIM),* Gundersen Health System's *Respecting Choices,* Aetna's *Compassionate Care,* and *Home-Based Primary Care/Independence at Home.* The common elements woven through these programs include care coordination, systematic advance care planning, palliation of symptoms and person-centeredness. The evidence-base for these ACM elements is derived from the established literature on complex patient care, chronic disease management, palliative and hospice care, and care transitions. In its ideal application, the ACM is delivered through a "team of teams" approach, that encompasses specially trained interdisciplinary teams of physicians, nurses and social workers, that operate in hospitals, outpatient settings, homes, and the community. These teams connect with patients, families, and each other in real time, and through the use of Electronic Medical Records (EMRs) and telephonic management.

MEASURES OF SUCCESS

The ACM's goal is to improve overall care from the identification – or diagnosis of - advanced illness through the end of life, a process which begins with enhanced patient identification and a robust referral system. Care outcomes include, increased patient engagement, care that reflects – and is more consistent with – the individual's preferences and values, and decreased costs associated with fewer Emergency Department visits, hospital days, Intensive Care Unit (ICU) days, and avoidable hospital readmissions. Measures of care coordination and communication incorporate additional important aspects of advanced illness care.[vii] *(See Exhibit 1 Graphic on Page 5)*

COMMUNITY ACTION MODELS

As health systems begin to shift towards population health approaches, it will become increasingly important to integrate non-medical social services and supporting resources with medical care in order to develop positive health outcomes and patient experiences. The recent Accountable Health Communities announcement from CMS is a welcomed step in the right direction, as it focuses on the importance of aligning clinical and community partners to better support social needs.

Even so, to make a substantive impact, these collaborations must move at "the speed of trust."[ix] That is, participants should expect and plan for partnerships that evolve over time and emphasize mutual respect for cultures, spirituality, traditions, and available community resources. The first step in building these relationships is to identify the right community resources, which can include: adult day services and adult night care, Aging Services Network, Area Agencies on Aging (AAA), Community Health Centers (CHCs), senior centers, Health plans that serve advanced illness or special needs populations, Meals on Wheels, Medicaid Home and Community-Based Services networks, Program of All-inclusive Care for the Elderly (PACE), and faith communities - especially those with existing health and social services (e.g., home visits to the elderly).

Programs, such as the *Alameda County Care Alliance (ACCA)* pilot, the *Congregational Health Network,* the *Respecting Choices* model, and others have demonstrated the effectiveness of developing strong partnerships with the faith community:

- **Congregational Health Network**: Founded in 2006, the *Congregational Health Network*, or "Memphis model," is a partnership between Methodist Le Bonheur HealthCare and 500+ places of worship. It is designed to support the transition from hospital to home for vulnerable populations in the Memphis, TN community. As a result of the model, enrollees showed lower mortality, utilization, costs, and charges, including reduction in readmission rates and time, increased referrals to hospice and home health, and higher patient satisfaction. The program's success to-date has depended on the sharing of medical information through technology, partnering with already established community groups, the development of a strong advisory committee, the ability to honor the wisdom and intelligence of liaisons embedded within the churches, and the trust and shared commitment that was built throughout the partnership.[x]

- **Alameda County Care Alliance (ACCA) Advanced Illness Care Program™ (AICP**): The ACCA, founded in 2013, is a faith community led and designed program to (1) Extend and strengthen the healthcare delivery system; (2) Improve the outcomes for those with advanced illness – and their caregivers – who are in need of care; (3) Reduce caregiver burden; and (4) Strengthen the community support infrastructure to meet the demand for advanced illness care. These goals are achieved through community, health system, and academic partnerships that implement a model which (1) Supports the selection and training of care navigators from the community – already embedded within the churches; (2) Trains clergy members to provide spiritual and decision-making support for ill parishioners; and (3) Trains a network of volunteers who provide social and emotional support to family caregivers and persons needing care.

- **Respecting Choices:** Respecting Choices was originally developed at Gundersen Health System in La Crosse, Wisconsin. The program uses established principles of learning theory to engage individuals with serious illness and improve their - and their surrogates' - understanding of the person's values and goals of care. This serves as a bridge between community-based organizations, such as places of worship, and health systems by ensuring a standardized approach to advance care planning through facilitators who are known to the community and embedded in churches and other community-based settings. As a result of the intervention, surrogates were better able to understand and know the values and goals of their loved ones regardless of age, culture, or diverse backgrounds, and that the care provided was aligned with their stated goals and preferences.[xi]

These programs – and others like them - show that health system-community relationships are synergistic, and not simply additive, when compared with similar, but unilateral efforts by providers or communities. They also suggest that there are often latent, underused resources that are not well coordinated between communities and healthcare providers, thus raising the potential for significant improvement when systematically linked. C-TAC's guiding hypothesis is that systematic linkage between community and health systems will yield better access to care and outcomes, including quality of care, greater patient and family satisfaction, and–as a result of better care coordination—lower costs of care for both individuals and commercial and public payers. However, this hypothesis has not been tested systematically or widely enough to allow policy and regulatory changes, which call for convincing data rather than assumptions or results from isolated programs. This will yield valuable input to national research priorities and the National Quality Strategy.

C-TAC has developed a Community Action initiative comprised of approximately 60 faith and community members from across the U.S., some of whom have implemented similar programs in other cities. C-TAC's next step is to summarize the findings from the various

pilot sites, and then explore opportunities to integrate this model with the ACM.

Moving from Concept to Action: Implementation of the ACM

The ACM has the ability to be implemented in a wide variety of healthcare settings. The effort can be led by an integrated health system, hospital system, health plan, physician group, or home-based provider (e.g., home health or hospice). In non-integrated settings, the model can be implemented and operated through aligned partnerships, wherein each entity owns a core component of the delivery model. In an Accountable Care Organization (ACO) structure, the health plan could furnish administrative support and telephonic case management, while a physician group could provide office- and clinic-based care, a home health agency could provide home-based palliative care, and a hospital could furnish inpatient palliative care. Exhibit II is a schematic outlining the potential roles for individuals and organizations in the ACM. *(See Exhibit 2 Graphic on Page 6)*

C-TAC is working with innovative health systems and plans to test the ACM, and provide further evidence to support policy, advocacy, and the spread of evidence-based person-centered care programs across the country. The findings will be shared at the 2016 National Summit on Advanced Illness Care - September 20th-21st – at the National Academy of Sciences Building in Washington, DC.

Policy Options to Support the Spread of the Advanced Care Model

Legislative and regulatory policy developments, like the proposed *Care Planning Act of 2015*, and the reimbursement for voluntary advance care planning through the CMS CY 2016 physician fee schedule, have demonstrated renewed attention on advanced illness care. In January 2015, Medicare—for the first time in the program's history - set clear goals for moving providers away from fee-for-service (FFS) payments toward value-based - or alternative payment models (APMs). These goals are not only changing the Medicare program, but they act as a catalyst for continued innovation by commercial health plans and providers. Within this context of shifts in the political landscape, the chart below outlines key features of the ACM, policy options to support the model, and opportunities to implement these policies. *(See Exhibit 3 Graphic on Page 7)*

Supported by a grant from The SCAN Foundation (www.TheSCANFoundation.org)—advancing a coordinated and easily navigated system of high-quality services for older adults that preserve dignity and independence.

The Coalition to Transform Advanced Care (C-TAC) is a national non-profit, non-partisan alliance of patient and consumer advocacy groups, health care professional and providers, private sector stakeholders, faith-based organizations, and health care payers committed to the vision that 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. For more information about C-TAC, visit TheCTAC.org

[i] Coalition to Transform Advanced Care (C-TAC). "Advanced Illness Key Statistics" https://docs.google.com/file/d/0B2Yr38cBOUqzUkhWLWJyZ25YQlU/edit

[ii] Institute of Medicine. 2014. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life.* National Academies Press: Washington DC. http://iom.nationalacademies.org/Reports/2014/Dying-In-America-Improving-Quality-and-Honoring-Individual-Preferences-Near-the-End-of-Life.aspx

[iii] For more information on these models, see the C-TAC and America's Heath Insurance Plan (AHIP)'s Foundation, Advanced Care Project Report (June 2015). Accessed: http://www.thectac.org/wp-content/uploads/2015/06/ACP-Report-6-18-15-FINAL.pdf

[iv] Smalley, D. Keynote at the C-TAC National Summit on Advanced Illness Care, March 3, 2015. https://www.youtube.com/watch?v=Rsv70bySu94; Berman, A. Washington Post (September 28, 2015). https://www.washingtonpost.com/national/health-science/a-nurse-with-fatal-breast-cancer-says-end-of-life-duscussions-have-saved-her/2015/09/28/1470b674-5ca8-11e5-b38e-06883aacba64_story.html

[v] Reinhard, S., Levine, C., and Samis, S. Family Caregivers Providing Complex Chronic Care, AARP & UHF

[vi] Vig EK et al. Why don't people enroll in hospice? Can we do anything about it? J Gen Intern Med 2010;25:1009-1019.

[vii] For more information on the Advanced Care Model evidence base and features, see The C-TAC and America's Heath Insurance Plan (AHIP)'s Foundation, Advanced Care Project Report (June 2015). Accessed: http://www.thectac.org/wp-

content/uploads/2015/06/ACP-Report-6-18-15-FINAL.pdf

[viii] For more information on the principles behind person-centered care, visit: http://www.thescanfoundation.org/learn-more-about-person-centered-care

[ix] Cutts, T., Community Action Models presentation at the C-TAC National Summit on Advanced Illness Care, March 3, 2015.

[x] Ibid.

[xi] Hammes, B. and Hill, C., Comprehensive Care presentation at the C-TAC National Summit on Advanced Illness Care, March 3, 2015.

[xii] Department of Health and Human Services. 2015. Better, Smarter, Healthier: In historic announcement, HHS sets clear goals and timeline for shifting Medicare reimbursements from volume to value. http://www.hhs.gov/news/press/2015pres/01/20150126a.html

EXHIBIT I: THE ACM SUMMARY

POPULATION DEFINITION

- Describe the population of people with chronic conditions, declining function and poor prospects for full recovery.
- Design a reliable and proactive identification process that operates through referrals and/or by predictive modeling using administrative-level claims and clinical data.
- Select and enroll patients that have a high probability of benefiting from intervention, i.e. those with advanced illness.
- Formulate discharge criteria to ensure continuity of care

INTER VENTION PRINCIPLES

- Serve "people" before "patients." Many people with advanced illness want to avoid being patients; i.e., want to live their lives to the fullest extent possible and avoid the dependent image of "patient". Define value, business model and metrics accordingly.[viii]

- Personal goals drive clinical goals. Shift engagement process to ensure personal relationships lead clinical relationships. To aid personal orientation, develop staff competencies in communication (e.g. health literacy) and engagement (e.g. conflict resolution and motivational interviewing). Care planning should first focus on the goals and values of the person with advanced illness rather than a myopic focus on the options of treatment of the person's disease. It is only with this approach that truly informed consent of the person can be obtained.

- Focus on personal preference defined as free informed choice by the person who has been educated about all available options for care.

CO RE OPERATIONAL ELEMENTS

Care Management

- Coordinate care across all clinical settings, over time as condition progresses, via communication in real time
- Move focus of care from hospital to home/community
- Provide care management through interdisciplinary teams led by an engaged physician
- Implement collaborative care coordination: engage individual, family, caregivers, physicians and other clinicians, other care managers, and community partners e.g. public agencies, churches, and community navigators

Advance Care Planning

- Promote advance care planning through continuing conversations over time, at ill person's pace, in safety and comfort of home
- Ensure that preferences for care are communicated, documented, available and followed by clinicians at all points of care

Treatment and Palliation

- Develop individualized care plan driven by personal preference and clinical/psychosocial/spiritual needs.
- Provide customized blend of disease-modifying treatment + palliative care
- "Tune" treatment to preferred level of symptom control
- Alter care plan as preferences evolve through illness progression

ENVIRONMENT :

Take advantage of existing or developing operational and financial innovation. Collaborate when possible with clinical integration networks (CINs), post-acute networks, ambulatory and home-based palliative care, complex case management, patient-centered medical homes, and collaborative networks that coordinate healthcare, public health and social services.

MES S A GING AND C OMMUNICATION:

Prioritize active, positive messaging and communication, e.g. "advanced care", that implies active, value-driven engagement with clinicians and the public.

PAY M E N T M O D E L :

Align incentives and provide a bridge from fee-for-service toward risk-based, performance-based and value-based reimbursement consistent with broader payment reform efforts.

EVALU ATION

- Standardize process and outcome metrics: personal experience of care, clinical outcomes and cost
- Implement measures that help guide implementation to help improve effectiveness of interventions

EXHIBIT II: ACM STAKEHOLDER ROLES IN IMPLEMENTATION

TYPE OF ORGANIZATION/ COMPONENT	CORE RESPONSIBILITIES
Ill Person and Family	• Expect clinicians to provide appropriate information to make medical decisions • Be open to engaging in shared decision making process • Demand that their goals and values drive their medical cares • Expect that their loved ones are included as key members of the care team and process
Health System Overall	• Program should be managed at the health system level to promote maximal coordination among hospitals, providers, extended care facilities, and home-based care providers • Maximal use should be made of home-based care providers and/or embedded care managers, along with associated care management infrastructure
Hospital	• Build out home visit and telephonic care management capabilities • Partner with community-based providers and home-based care providers (e.g. home health and hospice)
Medical Group	• Build out home visit and telephonic care management capabilities • Health Plan may provide case management services for Medical Group • Partner with hospitals to provide inpatient care management • Partner with home-based providers (e.g. home health and hospice)
Home Health or Hospice	• Partner with community-based providers • Build out telephonic care management capability and expand on its home visit capabilities • Partner with hospitals to provide inpatient care management • Create safeguards against home health or hospice referral inducement
Health Plan or Public Payer	• Provide support for program • Provide case managers to members and to medical groups where desired and appropriate • Approaches to aligning incentives to complement the clinical/care coordination model • Data capabilities/Informatics
Community-Based Organizations	• Serve as trusted communication link and advisors between underserved patient populations and • Provide decision-making support and resources • Coordinate social services • Partner with home-based providers (e.g. home health and hospice)

EXHIBIT III: PUBLIC AND POLITICAL OPPORTUNITIES TO SUPPORT THE ACM

CARE MODEL FE ATURE	SUPPORTIVE PUBLIC POLIC Y	POLITICAL OPPOR TUNITIES
Prioritize the person's voice through advance care planning	• Empower patients and increase awareness of the importance of advance care planning • Support portability of advance care planning documents across time and setting.	• Reauthorizations such as the Older Americans Act (OAA) that support public awareness • Medicare & You Handbook to engage Medicare beneficiaries • Legislative vehicles such as the Advance Planning & Compassionate Care Act that ensure validity of advance • Legislative vehicles such as the *Personalize Your Care Act* that support continuous advance care planning discussions over time
Sustainable payment systems supporting population management and risk-bearing models	• Develop and gather consensus around comprehensive quality metrics • Build on existing federal and state demonstrations and programs to replicate and scale effective advanced illness care programs	• Medicare Access and CHIP Reauthorization Act (MACRA) ◦ Alternative Payment Models (APMs) including ◦ Streamlining of quality measurement from (e.g.) Meaningful Use and Value-based Modifier Program • Medicare Advantage Stars Rating Program
Promote workforce efficiency and support interdisciplinary team training	• Empower patients and increase awareness of the importance of advance care planning • Support portability of advance care planning documents across time and setting.	• Reauthorizations such as the Older Americans Act (OAA) that support public awareness • Medicare & You Handbook to engage Medicare beneficiaries • Legislative vehicles such as the Advance Planning & Compassionate Care Act that ensure validity of advance • Legislative vehicles such as the *Personalize Your Care Act* that support continuous advance care planning discussions over time
Support care coordination and enhanced transitions	• Support the adoption of advanced illness care through already-existing federal programs	• Implement waivers through MSSP and Pioneer ACO programs for advanced illness care adoption • Promote the adoption and assessment of advanced illness care through patient-centered medical homes • Support the use of remote monitoring and telehealth through legislation • Pilot projects through CMMI • State waiver programs
Promote care management and system and social services integration	• Revise eligibility criteria for hospice	• Through legislation, expand the population eligibility for hospice and ease face-to-face and telehealth requirements