



Advanced Illness Policy Review:

The Landscape for Improving Advanced Illness Care in America

Coalition to Transform Advanced Care (C-TAC)

November 2013

Contents

FOREWORD.....	i
ABOUT CTAC.....	iii
EXECUTIVE SUMMARY.....	vii
METHODOLOGY.....	xiii
CONCURRENT ACTIVITIES.....	xiv
SECTION 1 • ADVANCE CARE PLANNING AND ADVANCE CARE DIRECTIVES.....	1
Overview	
Informal Proposals	
Formal Proposals	
Comments	
SECTION 2 • CONSUMER AND FAMILY CAREGIVER EDUCATION AND SUPPORT.....	17
Overview	
Proposals	
Comments	
SECTION 3 • PROFESSIONAL EDUCATION AND WORKFORCE DEVELOPMENT.....	27
Overview	
Proposals	
Comments	
SECTION 4 • PAYMENT REFORM AND QUALITY MEASUREMENT	35
Overview	
Informal Proposals	
Formal Proposals	
Comments	
SECTION 5 • RESEARCH	47
Overview	
Informal Proposals	
Formal Proposals	
Comments	
CONCLUSION.....	55
GLOSSARY OF TERMS.....	56

Dear Health Care Stakeholder,

This report – *Advanced Illness Policy Review: The Landscape for Improving Advanced Illness Care in America* – is a compendium of federal policy proposals aimed at improving care for people with advanced illness and providing support for those who care for them.

Seriously ill individuals and their families are especially vulnerable to the disjointed, fragmented and unresponsive care delivery that characterizes our health care system. Over the next two decades, the number of older Americans (those over 65) will nearly double to more than 72 million, or one in five of us. The vast majority of people with advanced illness will be in this age group. Most will face multiple, progressive, chronic illnesses over a period of years. This requires a transformed approach to care delivery, incorporating better management of symptoms and coordination of care across settings.

An important step in this process is gaining an understanding of current and past policy options influencing care delivery. This report collects and briefly describes policy proposals in the following areas: advanced care planning, consumer and family caregiver education, quality standards, professional education, payment and regulatory reform, health information technology and research.

The report is meant to be a useful tool in understanding the current climate of policy analysis and to assist in assessing the range of options that can impact and improve advanced illness care.

We welcome comments on these policy options and, more specifically, on what specific policies are now required to create a comprehensive policy agenda at the national level. Our purpose is to gather feedback and ideas from multiple sources and to utilize this feedback to create a recommended policy agenda for transforming advanced illness care in the United States.

While this policy agenda is being researched and developed, we intend concurrently to inform and advance the process by analyzing existing best-practice delivery models that ensure high-quality, coordinated care across all settings. There are a number of advanced illness care models that are having a significant impact, including on quality of care, quality of life (e.g. patient and family satisfaction) and by lowering costs. To accomplish this, C-TAC, in partnership with the AHIP's Foundation's Institute for Health Systems Solutions, has initiated the Advanced Care Project. The Project will identify, analyze and compare best practice clinical care models in order to: (1) help inform and shape the comprehensive policy agenda and (2) promote a best practice clinical models framework to health systems and others throughout the country.

We look forward to hearing from you. Please provide your comments and ideas. Working together, we can inform and influence national legislative and regulatory policy and promote best practices to create a better future and achieve 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.

Best regards,

Bill Novelli

Co-Chair, CTAC and
Professor, McDonough School of Business,-
Georgetown University

Tom Koutsoumpas

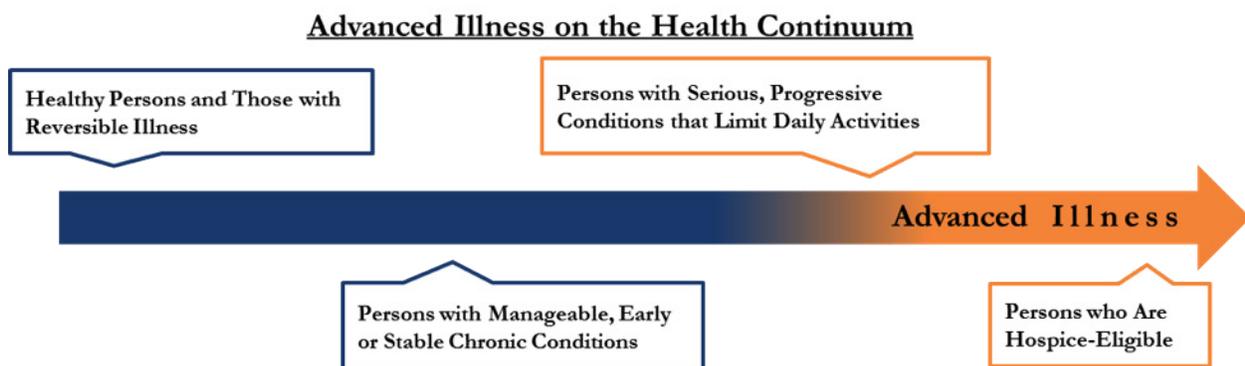
Co-Chair, CTAC and President, Caring Foundations

About C-TAC

Founded in 2011, the Coalition to Transform Advanced Care (C-TAC) is a national non-profit, non-partisan alliance of patient and consumer advocacy groups, health care professionals and providers, private sector stakeholders, faith-based organizations, and health care payers. The organization’s membership and leadership consists of a group of vibrant, diverse, and passionate stakeholders united by a common mission: to transform advanced illness care by empowering consumers, changing the health delivery system, improving public and private policies and enhancing provider capacity.

What is “advanced illness?” Advanced illness occurs when one or more conditions become serious enough that health and functioning begin to decline, active treatment may no longer lead to outcomes that patients choose, and care oriented toward comfort may take precedence over attempts to cure. Advanced Care is a comprehensive system of care management that integrates services for people with advanced illness across health care settings and over time. Advanced Care combines active treatment with palliative care, customized to match personal values and preferences as they evolve through the process of illness and adaptation.

C-TAC and its members strive to achieve high-impact, commonsense, and person-centered improvements for this targeted population and those who care for them. In so doing, we seek to effect change by developing and disseminating proven intervention-based care models, improving professional education, generating public demand and empowering consumers, and ultimately advocating for policy change to improve advanced illness care.



Since its inception, C-TAC has viewed its role in the broader health care community as a convener and catalyst for change for this population, bringing together the best ideas and most thoughtful, innovative leaders in advanced illness care. We are focused on four key directives, with particular attention to faith-based and cultural perspectives and to mobilizing unique stakeholders, including employers, to achieve improvements in each area:

- Analyzing and promoting **best-practice delivery models** that ensure high-quality, coordinated care across all settings;
- Disseminating innovative, inter-professional advanced care **education to clinicians** aimed at improving quality, shared decision-making, and improved medical care by cultivating respect, compassion and responsiveness in care delivery;
- Undertaking and supporting **public education and engagement** to help people make more informed decisions and to support delivery system and policy change; and
- Developing and **advocating** for federal and state legislative, regulatory, judicial and administrative policies, as well as private policies, to improve care for those with advanced illness.

We firmly believe that tackling the issue of advanced illness care requires simultaneous interventions in all of these areas and the building of unique partnerships that focus on the common good. It is through this process that we will ensure access to high quality, comprehensive, and person-centered care for all Americans that honors their dignity and is consistent with their wishes.

Our strength is derived from our vast network and collaborative, multifaceted approach to advanced illness management. We are unique in our approach of engaging all stakeholders under a unified alliance that is squarely focused on the advanced illness population. C-TAC is comprised of key workgroups and committees that lead a collaborative effort to advance several projects related to the ultimate mission all coordinated by a central staff. The leaders of and participants in these Workgroups continue to dedicate their precious time, tremendous expertise, and inspirational passion to the cause. We are so thankful to all of our members, contributors, and participants without whom we would have never been able to get to this point.

We built C-TAC to lead from the private sector with the theory that we first needed to better define best practices and better understand core innovations before we advocate for policy change. After much work, we are at a place where we are now ready to engage more definitively in the public policy debate and put forward solutions inspired by our members that will create a policy and regulatory environment conducive to the implementation of supportive, person-centered clinical models of care that is delivered by a compassionate, astute workforce, supports family, friends, and caregivers, and engages us all in an honest, understanding, and respectful discussion of our health care wishes throughout each individual's care journey.

Executive Summary

For decades, health care stakeholders have grappled with how to improve care for the seriously ill through changes in federal health policies both in Medicare and Medicaid programs. From the establishment of the Medicare hospice benefit in 1983 to the Patient Self Determination Act in 1990 and Medicare Modernization Act of 2003, changes in public policy have led to historic improvements in advanced illness care delivery. Yet, the combination of an aging Baby Boomer population and an American health care system that often ignores the wishes and desires of seriously ill patients proves that that much more can – and must – be done.

First convened in 2011, the Coalition to Transform Advanced Care (C-TAC) Policy & Advocacy Workgroup is charged with “providing ongoing strategic advice to C-TAC on ways the coalition can inform the policy process around advanced illness care” and ultimately “advocating for federal and state statutory, regulatory, judicial and administrative action and private policies to improve health care outcomes for those with advanced illness.” In pursuit of these objectives, the Policy & Advocacy Workgroup has worked to (1) identify and improve policy proposals that aim to achieve higher quality care for those with advanced illness and their families, and (2) collaborate and learn from the expertise of the three concurrent Workgroups within C-TAC to develop new policy proposals based on best-practice clinical models of care, professional education innovations, and communication strategies that will achieve C-TAC’s overall mission.

This report – the first in a two-part series -- represents a major step toward these objectives by mapping the universe of federal policy proposals to improve advanced illness care offered by lawmakers and stakeholders alike. The next report will build upon these proposals and those of the most successful private sector innovations in order to develop a future, comprehensive public policy agenda to improve quality and increase access the best advanced illness care for all Americans.

Key Findings

In evaluating the options outlined in the report there are preliminary overarching conclusions that help frame the current state of advanced illness care policy proposals:

1. Advance care planning, most notably through advance directives, and support for family caregivers appear to be the two subject areas where advanced care legislation is most evolved.
2. The number of both “formal” legislative proposals and “informal” proposals (those not written or offered in legislative language) specifically targeting the population with advanced illness is surprisingly limited. Of the over 50 policy options listed below, many were proposals that have been reintroduced in successive congressional sessions. Furthermore, the majority of formal proposals are fewer than five to ten pages and are not extensively drawn out (with the exception of the *Care Planning Act of 2013 authored by Senators Mark Warner (D-VA) and Johnny Isakson (R-GA)*). This creates an opportunity to advance new, innovative proposals that build on the best private sector models.
3. Many proposals have a cost associated with them or rely on authorizations for further funding making them subject to the congressional appropriations process.
4. Although some proposals have received considerable attention, many are still unknown to the broader set of members and stakeholders outside of the advanced illness community.

Furthermore, some legislative proposals in the realm of research, including Rep. Lois Capps’s (D-Ca.) 2009 H.R. 1032, the “Heart Disease Education, Analysis, Research and Treatment Act for Women Act,” and Rep. Capps’s H.R. 1078, the “Comprehensive Cancer Care Improvement Act of 2007” have successfully gathered bipartisan support and have drawn over 100 cosponsors. However, there remains a dearth of proposals in areas such as health information technology, quality measures, and payment reform. This absence of proposals in these areas creates both a challenge and opportunity for stronger party leadership and bipartisan collaboration.

Summary of Proposals

The proposals included in this report are categorized by the following major areas that impact advanced illness care delivery:

1. Advance Care Planning and Advance Directives

Widely recognized as a key component of advanced illness care delivery, proposals to create federal incentives for advance care planning and the execution of legal documents illustrating individuals' wishes have been both the central policy option to improve advanced illness care delivery and have been offered regularly over the past several congresses.

Based on the many proposals put forth, this report finds that expanding access to advance care planning services is a priority and will require a collaborative, multistep approach on the federal, state, and regional levels. This includes developing grants and incentives for the creation of state registries, requiring Medicare, Medicaid, and CHIP to cover and reimburse for voluntary advance care planning, and advocating for legislation to ensure advance directive portability. Other key initiatives utilize grassroots approaches and involve creating national advance care directive public awareness campaigns or 24-hour toll free hotlines to enhance consumer education.

To ensure the proper adherence to patient wishes and choices, several proposals offered in recent years demonstrate the importance that providers maintain up-to-date EHR systems that can readily share patient directives across care settings. On the federal level, the proposals show that this involves updating meaningful use standards to require EHRs to fully display patient ACDs & POLST documents. The policy options offered also show these records must also display information regarding patient families and caregivers. Other important initiatives and proposals involve the use of telehealth services and remote monitoring to promote a higher level of care for patients with advanced illness or chronic care management needs. Many ACO demonstration projects have experimented with telehealth technology and online communications to develop better methods for offering high quality, low cost care for this population.

2. Consumer and Family Caregiver Education and Support

Caregivers make up the backbone of long-term care services and supports, and thus many policy proposals have been offered to be responsive to the growing demand for their services. The policy options put forth by lawmakers and stakeholders based on the comprehensive review for this report show that providing a substantive network of emotional, psychological, and physical health support as well as educational and financial resources is essential to ensuring the well being of families and caregivers. Many legislative proposals have included provisions to increase tax credits and deductions for caregivers, expand counseling and mental health services, and provide additional education and training resources for family support.

3. Professional Education and Workforce Development

Advanced illness treatment requires a comprehensive, team-based approach to deliver high quality care. Providing special, individualized training in palliative care medicine for physicians, nurses, technicians, and all practitioners on the care team is the first step toward developing professional competence in areas relating to serious disease and advanced illness. This involves developing wide-range initiatives for both allopathic and osteopathic care teams to increase professional engagement in the palliative care and hospice arenas. For instance, the policy proposals reviewed show that financial incentives are an important resource for offering direct care workers continued training as well as to create awards and bonuses for facilities whose employees pursue additional specialization or certification.

4. Payment Reform and Quality Measurement

Proposals focusing on payment reform and quality measurement for the advanced illness population were an important component of the research for this report, led by the comprehensive Senior Navigation and Planning Act and Care Planning Act (both authored by Senator Mark Warner (D-Va.) that create a new coordinated advanced illness management benefit in Medicare and Medicaid. The review of policy proposals also shows that quality and survey assessments are crucial to developing best practice clinical models and delivering high quality

and low-cost advanced care. These quality assessments are essential in developing high-impact measures that will help reform payment, reimbursement, and delivery methods. This includes expanding Medicare, Medicaid, and CHIP benefits to offer additional palliative care and hospice services as well as sponsoring additional demonstration projects to study cost & utility of advanced illness services.

5. Research

The review of proposals shows that research is essential to (1) developing evidence-based protocols to enhance current advanced care delivery models (2) furthering our understanding of common of later stages of advanced illnesses such as cancer and Alzheimer's & other dementias. Research priorities include standardizing methods of assessing process and outcome measures and creating methods to properly distribute this information to providers. In addition, establishing grants and awards to the National Institutes of Health (NIH) as well as other federal agencies is key to expanding investigations into the effects of late-stage advanced illness.

Conclusion

We intend to continually update this document over time as additional policy proposals are added to the fold. Again, it is important to note that nothing in this report should be construed as an endorsement of any of the policy proposals by C-TAC or by any of the contributors to the report.

On behalf of the C-TAC Policy & Advocacy Workgroup, we hope this report serves as a helpful tool to identify recent high-impact public policy proposals – proposals that have the potential to ensure supportive, person-centered and effective care for all Americans struggling with advanced illness.

Mark Schoeberl & Charlie Sabatino

Co-Chairs, Policy & Advocacy Workgroup

Methodology

For the purposes of this first report, options that were studied were limited to the federal government. While there is significant impact that can be accomplished at the level of the state government, especially through long-term care, community-based support, and Medicaid and other health assistance programs, the extreme complexity of analyzing the options proposed by the 51 (50 states plus the District of Columbia) state governments as well as its interaction with the federal government would have required a report involving much more detail than the one before you. In subsequent reports C-TAC intends to look much more closely at the intersection of state and federal governments as well as work with state-based stakeholders to identify potential solutions that can be replicated in other locations and settings in different parts of the country.

The “advanced care” options detailed in this report were compiled through three primary means. First, we conducted a comprehensive search of the THOMAS database in the Library of Congress for relevant legislation proposed during the 109th through the 113th Congress, or from 2005 to the present. Second, we further conducted a search through the websites and public databases of information for all of the major professional and industry organizations that have a stake in advanced illness care including but not limited to organizations focused in hospice, palliative care, hospitals, and disease-specific advocacy groups. Finally, interviews were conducted with over 20 volunteers with in-depth and expert knowledge and who have extensive work experience in the policy environment for advanced illness care. The vast majority of the interviewees were members and active participants in C-TAC.

From this process, we categorized the proposals into “formal” and “informal”; formal meaning that they were packaged and formally introduced as a bill or regulatory proposal while informal was meant to capture broader concepts and ideas that may or may never been packaged into an official proposal. Non-medical, psycho/social and/or community support options were excluded from this search. Also too, related advanced care legislation concerning active duty military and veterans (and Native Americans via Indian Health Service reforms) were excluded - absent a few bills identified for exemplary purposes. The exclusion of these options is an intentional oversight to narrow the options to those that would have the most immediate and sure impact on the health care experience for Americans dealing with advanced illness.

After the identification of the various formal and informal proposals, we placed the proposals in the one of the eight pre-identified spheres of advanced illness care and analyzed the set for basic trends and context. We did not attempt to identify strengths and weaknesses of various proposals as different stakeholders would consider and judge the merits of the proposals in different lights. This was rather meant to provide an objective look at the current situation for the various proposals.

Concurrent Activities

Through the process of compiling this report, C-TAC also encountered several concurrent policy and advocacy activities of other organizations, some active C-TAC members and some cordial collaborative efforts, working in the advanced illness care space that have the opportunity to make a significant contribution and positive impact on the state of advanced illness care. The ultimate success would change the findings and perspectives of this report, and we feel it is important to highlight those efforts here. On the policy development front, the efforts below could be particularly important in future advanced illness care reform:

- RAND Health, led by Dr. Karl Lorenz, is presently completing the National Institute of Nursing Research (NINR) and California Healthcare Foundation-funded “Trajectories and Palliation Study” (TAPS). The TAPS is intended to “inform public discussion of the role of palliative and end of life care in Medicare and that the modeling of these policy options will provide evidence regarding likely patient, caregiver and health system outcomes of policy to inform policy advocacy and rational policy making.”
- The Institute of Medicine’s (IOM) Committee on Transforming End of Life Care is, through this year, conducting public meetings throughout the US in preparing for an anticipated 2014 consensus report.
- After completing in late 2011/early 2012 its Palliative and End of Life Care Project (discussed below), the National Quality Forum (NQF) intends to revisit quality measures in this realm in 2014.
- Emory University’s Ken Thorpe recently announced a new coverage option for Medicare called “Medicare Integrate” that would be added to traditional Medicare and Medicare Advantage coverage. “Medicare Integrated” would largely provide care coordination services moreover for chronically ill Medicare beneficiaries.
- The VA continues to do substantial work in palliative care, in part, since veterans currently account for nearly one in four civilian deaths annually.

In addition to these policy development efforts, there are several active advocacy efforts organized behind some of the formal and informal policy proposals below. In particular, there is strong support from several industry and professional organizations actively supporting specific proposals around advance care planning, professional education, and palliative care. If enacted into law, this would represent a significant step forward for the broader advanced illness care community.

Section 1

Advance Care Planning and Advance Care Directives

“Advanced illness is as predictable as anything that may arise in our lives, but when it arrives, we are woefully unprepared”

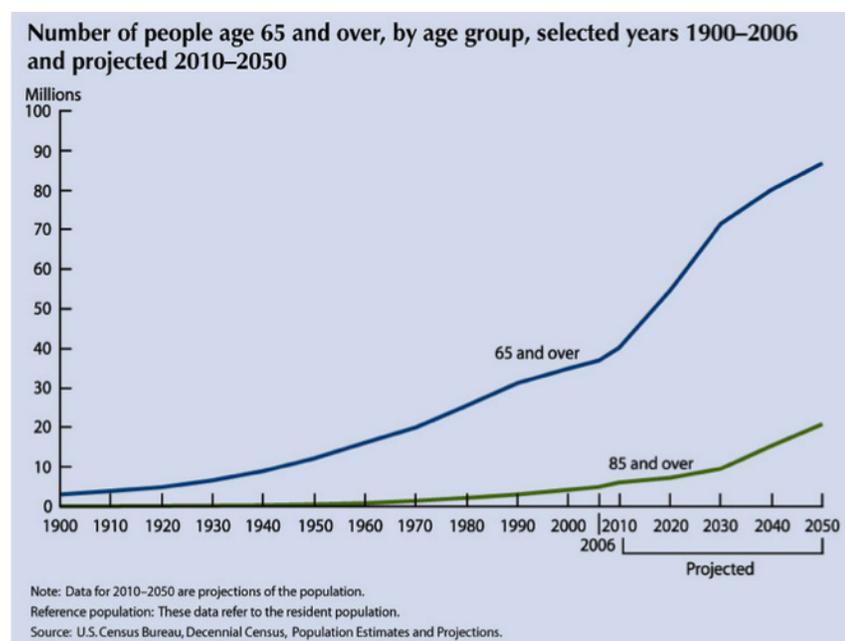
- Nancy Brown, American Heart Association

Section 1

Advance Care Planning and Advance Care Directives

Overview & Background

The Administration on Aging reports that the number of Americans over 65 reached 41.4 million in 2011 predicting a rise in elderly populations who may suffer advanced illness. Furthermore, in 2009-2010, approximately 45 percent of adults 65 and over reported living with two or more chronic conditions. Delivering quality, person-centered care to these individuals calls for greater emphasis on information delivery ahead of time to ensure that patient preferences and dignity are honored when advanced – and ultimately terminal – illness may occur. A crucial component of this process is advance care planning. Advance care planning is a process of interaction, typically between trained health professionals and patients and their family members, regarding decision-making about future health care events. This process assists patients so they can more completely understand the information and themselves, more deeply reflect on their beliefs, values, and goals, and engage in insightful discussion with their loved ones.



Lack of effective communication among patients, families, and clinicians can cause confusion regarding the patients' beliefs, values, and goals and how these play into choices concerning treatments, benefits of procedures, and overall disease prognosis. Advance care planning can help prepare people, their families, and their providers to make difficult decisions in accordance with the ill person's wishes during serious illness.

Studies have shown that those over 65 years old who have engaged in advance care planning with their doctor or other medical professional have demonstrated increased patient satisfaction. In addition, patients who talked with families or physicians about their care preferences had less anxiety, more ability to influence their care, and greater comfort levels than before these discussions.

Research has also shown that individuals living with an advanced illness such as cancer are more likely to receive the treatment they prefer when their treatment options are discussed with medical professionals. It also shows that advance care planning can improve caregiver quality of life, reduce emotional trauma and depression, and diminish regret in surviving family members following the death of a loved one. According to recent studies, disease-specific advance planning for illnesses such as heart disease can also increase hospice election rates and significantly improve family members' understanding of the patient's goals of care when treatment outcomes are bad.

The advance care planning process allows patients to clarify and articulate treatment preferences in preparation for the potential onset of advanced or fatal illness and to record these plans in some type of written care plan. There are various means of recording a care plan. One well-known type of care plan is a statutory advance directive document. Common forms of such advance directives (ACDs) include living wills and Durable Powers of Attorney for Health Care (DPAHC). DPAHCs allow patients to designate a surrogate decision-maker in the event that they are unable to do so. Advance care planning also occurs through discussion between physicians and patients (or patients' medical decision-maker) that are documented in the medical record, or that result in a set of portable medical orders such as Physician Orders for Life-Sustaining Treatment (POLST). POLSTs (also known as MOLSTs or MOSTs) allow patients to specifically document the kind of treatment and end-of-life care they would like to receive.

In recent years, more attention has been given to the process of advance care planning as a life-long process that changes across adulthood as one's health and goals of care evolve. For a healthy adult, the key component of ACP involves naming an appropriate proxy in the event that the individual is temporarily or permanently incapacitated, cannot make health care decisions, or when a sudden, severe, permanent cognitive loss is so bad that it would lead to the desire for changing the goals of medical treatment. For individuals living with a

significant chronic or advanced condition(s), ACP still prioritizes naming a proxy but also focuses much more on the individual's goals of care and treatment preferences under possible serious medical scenarios specific to their advanced illness. For persons with serious, progressive conditions or advanced frailty whose life expectancy is very limited, planning still starts with having an informed proxy and predicting critical choices that may be faced in light of the person's current medical condition. The prominent tool for documenting such a care plan is a Physician Orders for Life-Sustaining Treatment (POLST), which creates a clear plan of care for critical decisions such as whether to attempt CPR and how to treat life-threatening organ failure.

POLST forms serve as portable medical orders that follow the patient across care settings, are honored in all settings, and are reviewed when the patient's venue of care or medical condition changes or when the patient or proxy desires a change. POLST began in Oregon in the early 1990s and now operates in about 20 states, although program names and procedures vary. For example, it is called Medical Orders for Life-sustaining Treatment (MOLST) in New York; Physician Orders for Scope of Treatment in West Virginia; and Medical Orders for Scope of Treatment (MOST) in North Carolina.

The most common clinical rule of thumb for determining who is appropriate for POLST is whether the clinician would be surprised if the patient were to die within the next year. POLST has been promoted as an effective way to ensure that the wishes of seriously ill persons are known and honored across transitions in care, an important consideration for this patient population. As with all forms of advance care planning, the quality of the conversations behind the decision-making is the critical element of quality patient-centered care and ensures that true informed consent is achieved.

In a collaborative, community advance care planning project implemented in La Crosse, Wisconsin (Respecting Choices®), the dominant health systems redesigned the interactions with patient so that advance care planning became the routine of care and care plans were systematically stored and available to health professionals at all sites for decision-making purposes. As a result, at the time of death, 96% of patients had completed a written care plan, care plans were available to the treating physician 99% of the time, and in 98% of cases, medical treatment was delivered in compliance with patient's documented preferences.

Lastly, health information technology reform is a key priority needed to ensure full adherence to patient wishes and directives. Compared to other large economic sectors, health care has lagged in the adoption and use of health information technology. However, with substantial government support beginning in 2009, the health care industry has made substantial progress in the adoption and use of HIT. By 2011, 54% of physicians adopted Electronic Health Record (EHR) systems and among physicians in larger practices (11 or more partners) this number was 86%. Additionally, per the American Hospital Association, 44 percent of hospitals had at least a basic EHR – a 9 percent increase from 2008. Still, substantial challenges impede in HIT adoption and use. For instance, according to the Centers for Medicare and Medicaid Services (CMS), only slightly more than a third of hospitals and only 11 percent of critical access hospitals met Stage 1 meaningful use and no providers have yet meet Stage 2 meaningful use.

In 2009, the American Recovery and Reinvestment Act (ARRA) established the Health IT Standards Committee and Health IT Committee. The Health IT Policy committee creates recommendations for improving the national health information infrastructure and is comprised of several subcommittees including the accountable care workgroup, certification/adoption workgroup, information exchange workgroup, quality measures workgroup, and meaningful use workgroup among others. The meaningful use workgroup provides short-term and long-term recommendations through three different stages of “meaningful use” – Stage 1 that investigates basic standards for maintaining health records and exchanging patient data, Stage 2 which focuses on enhancing coordination of patient data and ways to better implement test results into the system, and Stage 3 that examines how to develop higher-level quality, safety, and efficiency standards to improve EHR systems.

History

In 1990, the Patient Self Determination Act (PSDA) was signed into law. The PSDA requires many hospitals, home health agencies, nursing homes, health plans, hospice providers, and other health institutions to provide information to patients about advance directives upon admittance to a facility and to record whether the patient has an advance directive. However, the PSDA fell short in addressing the actual process of advance care planning as well as portability – a key provision that would allow directives to be universally recognized across state borders.

Advance care planning has received some attention in recent years. In 2008, Congress added an end-of-life planning consultation to initial preventive physical exam under the Medicare Improvements for Patients and Providers Act (MIPPA). Although advance care planning consultations have succeeded on a local and regional basis in certain areas of the country, public awareness and utilization of advance care planning remains limited. A recent poll conducted by Pew Research Center approximates that only 20 to 30 percent of healthy Americans have created an ACD.

Advance Care Reform Informal Proposals

Many consumer groups, professional associations, disease groups, and others have actively advocated for further promulgation of advance care planning and ACDs. In general, these proposals fall into the following three categories:

1. Providing and paying for advance care planning
 - Require coverage of voluntary advance care planning under Medicare, Medicaid, and CHIP;
 - Reassess the Patient Self-Determination Act (PSDA) and include a provision clarifying that a patient's directive can be presumed valid if written, signed, and witnessed.
 - Requiring advance directives to be incorporated into a prominent part of the medical record.
 - Requiring facilities provide at admission an opportunity to discuss advanced care planning with an appropriately trained individual.

2. Improving legal portability and requirements to execute
 - Require Department of Health and Human Services (DHHS) to complete a study examining ACD portability and provide a time table for developing a national ACD registry;
 - Recognize any genuine expression of a person's wishes but allow a provider or organization to decline to honor directives deemed invalid;
 - Direct the Secretary to study state and regulatory activities regarding ACDs & POLST storage and request the GAO to study quality and cost;
 - Award competitive grants to establish and operate state ACD registries.

3. Public education
 - Create a national campaign to generate public awareness of ACDs;
 - Develop an online advance care planning database of ACD materials including a tool kit;
 - Launch a website for providers under Medicare, Medicaid, CHIP, IHS and others to highlight resources on patient decision-making rights;
 - Establish a 24-hour toll free telephone hotline;

- Award state grants to provide advance care planning services to Medicare and Medicaid beneficiaries;
- Amend the Legal Services Corporation Act to authorize financial and legal assistance for advance care planning/ACDs.

4. Health IT Standards

- Require stage three of meaningful use include patient's ACD, POLST and/or other related documents and identify family caregivers;
- Encourage or require DHHS to partner with companies offering smart phone/mobile applications that help create ACDs and other related documents;
- There have been numerous proposals to enhance the use of information technology in electronic communications and remote monitoring. For example, the Commonwealth Fund estimates that fewer than seven percent of providers used electronic communication in 2008 even though it is widely considered a safe and efficient means of transferring data. The VA is likely the most frequent user of telehealth technologies. Approximately one million veterans use some type of VA telehealth service including (1) sharing electronic medical records family caregivers, (2) conducting prosthetic check-ups, and (3) utilizing a wide range of other examination or counseling appointments including PTSD counseling. The VA states its telehealth program has reduced bed days for veterans by 58 percent and hospital admissions by 38 percent.

Formal Advance Care Planning and Advance Directive Proposals

Many federal legislative proposals related to advance care planning and advance directives have been offered by a number of entities (including Congress and the executive branch).

Congressional Budget Office (CBO): In 2008, the CBO included in their semi-annual *Budget Options* report a proposal titled “Implement Policies That Encourage the Use of Advance Directives” (Option 104). This policy would ensure ACD portability and establish (1) a nationwide ACD education campaign, (2) a centralized and accessible ACD database, (3) a national assistance service center, and (4) a related DHHS advisory board. In the report, CBO estimated that mandatory savings within a 10-year budget window would amount to \$100 million and also predicted a 110 million increase in federal discretionary spending.

Care Planning Act (S 1439)

2013

Senator Mark Warner (D-VA) - Finance Committee; 1 cosponsor

The bill would create a new Medicare and Medicaid benefit for advanced illness planning services. An interdisciplinary team would (1) identify and articulate patient goals, (2) discuss the range of treatments that align with these goals, (3) document the plan, (4) notify appropriate service providers, and (5) include relevant training materials for the patient and caregiver. Eligible beneficiaries would receive the benefit no more than once a year. These planning services would be reimbursed by Medicare Part B as well as Medicaid. The legislation also would require CMMI to conduct a five year advanced illness care coordination services demo for patients in need of assistance for two or more activities of daily living (ADLs). It would require advance care planning materials be included in the Medicare and You Handbook, create a care planning advisory planning board to advise the Secretary, and direct providers to have certain policies and procedures related to advance care planning and directives. In addition, the legislation authorizes the Secretary to award grants to develop advance care planning materials, study the electronic storage of ACDs, and authorize the GAO to address related quality and cost issues.

Personalize Your Care Act (HR 1173)**2010, 2011, 2013***Representative Earl Blumenauer (D-OR) - Ways and Means Committee; 14 cosponsors*

This bill includes provisions for ACD portability and sponsors grants to develop statewide POLST programs. It also requires that any authentic expression of patient wishes be honored in the absence of an ACD. It would also authorize Medicare coverage of voluntary advance care planning every five years or in the event of a change of health status.

Personalize Your Care Act (HR 1589, HR 5795)**2010, 2011***Rep. Earl Blumenauer (D-OR)-Ways and Means Committee; 5 cosponsors*

This bill requires EHRs to display current ACD and POLST.

Senior Navigation and Planning Act (S 3684)**2009, 2012***Senator Mark Warner (D-VA) - Finance Committee; 0 cosponsors*

This legislation endorses a national public education campaign, establishes an ACD toll free information line, and includes provisions for ACD portability. It also requires advance care planning materials to be included in the “Medicare and You Handbook,” directs the Secretary to study ACD and POLST storage, and requests the GAO to study the cost and quality of proposed legislation.

Advance Planning and Compassionate Care Act (S 1150, HR 2911)**2009***Senator John D. Rockefeller (D-WV) - Finance Committee; 7 Cosponsors**Representative Earl Blumenauer (D-OR) - Judiciary Committee; 3 cosponsors*

This act would have (1) authorized coverage of advance care planning under Medicare, Medicaid and CHIP; (2) created a national advance care planning campaign; (3) developed a federal toll-free hotline for consumer education; and, (4) launched an online advance care planning toolkit. It would also have created grants for state ACD registries, developed an online website for advance care planning, authorized Medicaid transformation grants for advance care planning, sponsored curriculum for continuing education credits, and endorsed the use of telemedicine services.

Advance Directive Promotion Act (HR 3253)**2009***Representative Sander Levin (D-MI) - Ways and Means Committee; 6 cosponsors*

This bill would have required ACDs be recognized universally, created a national public education campaign as well as a toll free ACD telephone hotline, and required an “end of life planning consultation” during an initial preventative physical examination.

Life Sustaining Treatment and Preferences Act (HR 1898)**2009***Representative Earl Blumenauer (D-OR) – Ways and Means Committee; 5 cosponsors*

This act would have authorized Medicare coverage for consultations regarding orders for life sustaining treatment, established state grants for POLST programs, and created a clearinghouse of information on these programs and consultations.

Comprehensive Cancer Care Improvement Act (S 2790, HR 1078)**2006, 2008***Senator Mary Landrieu (D-VA) – Finance Committee; 5 cosponsors**Representative Lois Capps (D-CA) - Ways and Means Committee; 117 cosponsors*

This bill would have provided for: (1) advance care planning services; (2) a two-year Medicare demonstration to pay for comprehensive cancer care symptom management; and, (3) multiple grants to improve palliative care symptom management programs. It would also have required the National Institutes of Health (NIH) to establish grants for palliative care research and provider education.

Advance Directive Promotion Act (HR 5702)**2008***Representative Sander Levin (D-MI) - Ways and Means Committee; 18 cosponsors*

This bill would have required Medicare providers to note the presence or absence of an ACD in a patient’s medical record. It also would have done the following: (1) required ACD portability; (2) required end-of-life planning in initial physical examinations; (3) established a 24-hour hotline regarding advance care planning and hospice care services; and, (4) funded a national public education program to increase advance care planning awareness.

Advance Directives Improvement and Education Act (S 347 and HR 2058) 2005

Senator William Nelson (D-FL) – Finance Committee; 14 cosponsors

Representative Sander Levin (D-MI) – Ways and Means Committee; 33 cosponsors

This act would have: (1) provided Medicare coverage for advance care planning consultations; (2) endorsed ACD portability; and, (3) allowed providers to decline to honor ACDs deemed inauthentic. It also allocated funds to increase public awareness of ACDs.

Advance Directive Education Act (S 570) 2005

Senator William Nelson (D-FL) – Finance Committee; 2 cosponsors

This act would have encouraged patients to discuss issues relating to individual and state rights in order to make important decisions concerning medical care and advance directives.

Comments

In 2010, CMS proposed a Medicare regulation to authorize voluntary advance care planning consultations as part of the Medicare annual wellness exam but five days later reversed this proposed rule. A similar proposal was also dropped from the Affordable Care Act earlier in the year due to political arguments about the intent of the provision. However, this attempt demonstrated that advance care planning could be initiated and endorsed via regulatory rulemaking.

Some approaches to undertake advance care planning have not been effective. For instance, developing a patient plan for all future health possibilities when patients are relatively healthy or utilizing a single type of care plan have not been successful. Such advance care planning strategies are often based on hypothetical future scenarios, cannot account for every circumstance, and may only apply to certain diseases or conditions. Some experts argue that such onetime approaches to advance care planning have proven counterproductive because the forms used are often legalistic, intimidating, and push the focus away from ongoing advance care planning conversations between the individual and his/her providers, family members and/or health care proxies. A more successful approach is to begin planning in stages when an adult is relatively healthy and then review and revise this plan when a progressive, life-limiting illness occurs and serious complications are occurring. A very specific plan is created that is often expressed in medical orders when death would not be a surprised in the next 12 months.

Many adults have been reluctant to plan for a time when they may be ill or dependent and may need help, although they worry about these issues. While the reasons for this reluctance are complex, many do not engage in planning because they do not know how to have the conversation, what topics to include, and which tools would be the most helpful and effective. Those 65 and older are more likely to talk with their children about what to do with their possessions than their preferences for care in a medical emergency. Patients and families have great difficulty in making care decisions as serious illness moves into the last stages. Too often, advance directives provide little support in the actual care decisions that have to be made for specific medical conditions.

To practically know and honor a patient's care plans, it is necessary to be able to document this plan in some record that can be shared with providers in expected settings of care and over time. One solution is the creation of state ACD registries. Unfortunately, potential operational issues have arisen in ACD state registries. Many have had low participation and access and use rates and some states charge a fee for registering an ACD that may deter low-income families from participating. Additionally, only few states contact registrants to update registry information. A more feasible solution is to design EMRs that can effectively store and retrieve all types of care plans and to connect these EMR to regional or state health information exchanges. This solution is more economically attractive than a stand-alone ACD registry. It keeps the care plan more connected to ongoing care and allows for continual updates.

Recognizing these challenges, a growing number of researchers suggest that efforts around advanced illness care should focus on ensuring that proper mechanisms are in place for shared discussion and decision-making among the triad of patients, family members and physicians at the time when the illness is getting more serious and complications can be more clearly anticipated. As health care systems move toward greater use of shared decision making in care delivery, under compliance with the Patient Protection and Affordable Care Act, it is critical to ensure that patients and families understand their care options, the varied effects different courses of treatment will have on their goals, and that their wishes, in fact, will be honored. This requires not only a health system that helps patient and families create care plans based on their goals of care, but also the ability to provide the services in way that the patient will find most supportive. So as we look for a shift in policy to pay for advance care planning services, we should be assured that the advance care planning services provided are effective and can be generalized to large populations.

Recording the presence or absence of an ACD – for patients 65 or older only – is an optional menu item for hospitals in stage one and stage two meaningful use criteria. Stage three proposed criteria make it a core requirement. The challenge persists in getting ACD, POLST or related other document/s in an EHR that is fully portable across state lines. This issue remains unresolved and often times ACDs are simply recorded as absent or present. There have been unsuccessful attempts by meaningful use policy committee members to record ACDs in EHR free text. The policy committee is planning a listening session on this issue to learn how they can make progress in documenting ACD content and ensuring portability. The lack of HIT use in post-acute care and long-term services and supports impacts individuals with advanced illness and potentially the coordination of their care and its quality.

However, even if advance care planning mechanisms and documents were fully recorded in EHR systems, there are broader policy challenges for HIT beyond those that pertain solely to advanced illness care. For example, in the implementation of EHR systems, in addition to the need to promote more use, stakeholders are still working through problems of compatibility, inter-operability, and user-friendly interfaces. Currently, most EHR systems are not capable of communicating with each other, which means that advance care planning documents might not even be able to be accessed even if they are fully recorded. For example, if an individual has his or her AD recorded in one system, if they present themselves for a health intervention at a physical location using another system, then that organization might not be able to extract the information necessary to follow the individual's wishes. Therefore, while there is great potential for HIT to further person-centeredness in advanced illness care, there are also broader, common policy challenges that must be addressed before that potential is fully realized.

In addition, there is also the need to observe and test outcomes for many telehealth and HIT technologies. They are simply too recent to have collected much data. On the advance care planning front, there are smart phone and mobile applications that can encrypt and store directives a the company's secure database that is accessible to providers. On the telehealth front, data out of the VA and other technologically sophisticated health care providers indicate that strong telemedicine components in advanced illness care approaches can be highly effective. However, with all of these technologies, we need to continue to monitor data collection from these interventions to determine how to maximize impact for individuals and families facing advanced illness.

Section 2

Consumer and Family Caregiver Education and Support

We know that family caregivers provide help with activities such as bathing and dressing, shopping, cooking and preparing meals. We also ask caregivers to do things that would make even nursing students tremble; it's important that we understand the scope of this new normal.”

- Susan Reinhard, AARP

Section 2

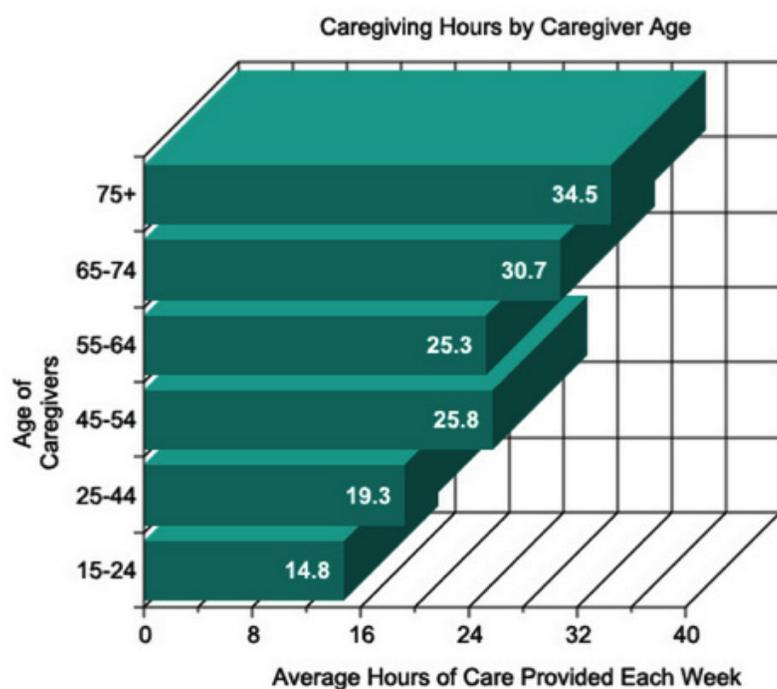
Consumer and Family Caregiver Education and Support

Family caregivers play a critical role in ensuring high-quality care for those with advanced illness. The National Alliance for Caregiving and AARP reported in 2009 that within a 12 period, an estimated 65.7 million people in the US have served as unpaid family caregivers to an adult or child. About 28.5 percent of the respondents surveyed reported being caregivers.

Caregiving can place great burdens on individuals. The National Alliance for Caregiving and AARP reported that caregivers spend on average 20 hours per week providing support to family members. The majority of these caregivers are female (approximately 66 percent). Professionally, caregivers may incur lost wages or lose workplace promotions and retirement savings as a result of their time spent caring for another. Furthermore, according to the Family Caregiver Alliance, an estimated 40-70 percent of caregivers may suffer from symptoms of depression. A quarter of that population may suffer from severe depression.

The following proposals seek to endorse mandatory disease and prognosis right-to-know laws for both curative and palliative care. This includes clarifying the sickness “trigger” for patient disclosure, identifying providers

who should offer patient counseling, providing referrals for psychosocial evaluations, and determining the range of choices that must be disclosed. Future proposals may include provisions to incorporate caregiver information and the shared decision making process of patients suffering from serious illness into electronic medical records.



Formal Consumer and Family Caregiver Education and Support Proposals

Alzheimer's Caregiver Support Act

2013

Rep. Maxine Waters (D-CA) – House Energy & Commerce Committee; 32 cosponsors

This bill authorizes the Secretary of the Department of Health and Human Services (DHHS) to design grants for both public and non-profit health providers expand training and support services for families and caregivers supporting Alzheimer's patients.

Care Planning Act (S 1439)

2013

Senator Mark Warner (D-VA) - Senate Finance Committee; 1 cosponsor (John Isakson)

This act includes a provision that authorizes DHHS to develop quality measures to evaluate the efficacy of advance care planning services. It provides in-home support services for individuals and caregivers via the Advanced Illness Care Coordination Services Project and documents caregiver goals and treatment preferences. The act also establishes a Care Planning Advisory Board that represents the interests of family caregivers and promotes best-practice communications methods to better inform family caregivers on advanced illness. It also directs HHS to study how hospitals, SNFs, hospice programs, and home health agencies carry out treatment plans and inform family caregivers. Finally, it supports the development of instructional materials and online modules to help caregivers and individuals understand the process of advance care planning.

Adult Day Center Enhancement Act (HR 3221)

2013

Rep. Barbara Lee (D-CA) - House Committee on Energy & Commerce; no cosponsors

This bill provides grants to improve access to respite services for caregivers supporting patients with progressive neurological diseases including Parkinson's and Multiple sclerosis.

The Americans Giving Care to Elders (AGE) Act (S 1485)

2013

Senator Amy Klobuchar (D-MN) - Finance Committee; 1 cosponsor

The bill would establish a federal tax credit and allow families caring for certain aging family members to qualify for a tax credit up to \$6,000.

The Long-Term Care Insurance Consumer Right-to-Know Act (S 1473) 2013

Senator Amy Klobuchar (D-MN) – Health, Education, Labor, and Pensions Committee; 0 cosponsors

This bill aims to help consumers understand what their policy covers and requires insurance companies to provide a one-page standardized disclosure form to consumers after the purchase of a long-term care policy.

The Long Term Care Integrity Act (S 1481) 2013

Senator Amy Klobuchar (D-MN) – Health, Education, Labor, and Pensions Committee ; 0 cosponsors

The bill calls for the creation of an independent, third-party review board to address claim denials by long term care insurance companies.

Older Americans Act Amendments (S 1028) 2013

Senator Bernard Sanders (I-VT) – Health, Education, Labor, and Pensions Committee; 18 cosponsors

This bill reauthorizes appropriations for FY 2014-2018 for family caregiver support provisions, directs DHHS to create state grants to assess family caregiver needs, and establishes a national resource center for family caregiving.

Americans Giving Care to Elders (AGE) Act (S 3226) 2007, 2009, 2012

Senator Amy Klobuchar (D-MN) – Finance Committee; 1 cosponsor

This act allows for a caregiver tax credit for up to -\$6,000 of the eldercare costs incurred for parents or grandparents. It also authorizes increases in Older Americans Act (OAA) funding for the National Family Caregiver Support Program through FY 2015 and establishes a national resource center on family care giving.

Strengthening Services for America's Seniors Act (S 1819) 2011

Senator Hebert Kohl (D-WI) – Senate Health, Education, Labor, and Pensions; 1 cosponsor

This bill directs the Assistant Secretary for Aging in DHHS to authorize state grants to establish programs to assess the needs of family caregivers.

Social Security Caregiver Credit Act (HR 2290) 2011

Rep. Nita Lowey (D-NY) – House Ways and Means Committee; no cosponsors

This act requires caregiving for a dependent to count as creditable work activity for up to five years when calculating Social Security credits.

Direct Care Job Quality Improvement Act (S 1273) 2011

Sen. Bob Casey (D-PA) – Sen. Health Education, Labor, and Pensions Committee – 8 cosponsors

This bill allows home care workers to receive minimum wage and overtime pay. It also establishes state grant programs to improve recruitment and training of direct care workers.

Caregiver Assistance and Relief Effort (CARE) Act (S 2958) 2010

Senator Robert Menendez (D-NJ) - Finance Committee; 0 cosponsors

This bill allowed for caregiver tax credits for family members with long term needs as well as tax deductions for long term care insurance premiums. It also amends the Older Americans Act of 1965 to extend funding through FY 2014 for the national caregiving support program. Services include directing caregivers to proper resources and assistance, providing individual counseling and caregiving training, and offering respite care and supplemental services.

Caregivers and Veterans Omnibus Health Services Act 2010

Senator Daniel Akaka (D-HI) – House Veterans’ Affairs Committee; 7 cosponsors

This bill directs the Secretary of Veterans Affairs to expand mental health services, respite care, and monthly stipends for caregivers of veterans undergoing medical discharge, recuperating from serious injury, or in need of personal care services.

Elder Caregiver Support and Information Enhancement Act (HR 519) 2009

Rep. Steve Israel (D-NY) – Education and the Workforce Committee; 9 cosponsors

This act authorizes \$250 million in funds for the National Family Caregiver Support Program (NFCSP) for FY 2010-2012. It also provides \$10 million for the operation of the National Clearinghouse for Long-Term Care Information for FY 2010-2012.

Retooling the Health Care Workforce for an Aging American Act (S 245) 2009

Senator Hebert Kohl (D-WI) – Health, Education, Labor, and Pensions Committee; 7 cosponsors

and Representative Janice Schakowsky (D-IL) – Education and Commerce Committee and Education and Labor Committee; 11 cosponsors

This bill provided for (1) the creation of family caregiving training materials under the Older Americans Act (2) the creation of information and referral protocols for family caregivers and (3) the development of training competencies for personal or home health aides. This bill also includes a provision under Medicaid to assess family caregivers' needs and provide resources to those providing support to beneficiaries who qualify for home and community-based services.

Caregiver Assistance and Resources Enhancement Act (HR 3155) 2009

Representative Michael Michaud (D-ME)– Veteran's Affairs Committee; 9 cosponsors

This bill enabled the VA to offer various services for family and non-family caregivers providing non-institutional extended care for disabled veterans, including educational sessions, stipends and access to support services, counseling and mental health services, respite care, medical care for family caregivers, and travel stipends for outpatient care. It also directs the Secretary to conduct caregiver surveys and report results to the veterans' committees.

Medicare Transitional Care Act (S 1295) 2009

Senator Jeanne Shaheen (D-NH)– Senate Finance Committee; 6 cosponsors

This bill expands Medicare Part B coverage (Supplementary Medical Insurance) to include benefits for transitional care services for qualified beneficiaries following discharge from a hospital or critical access hospital. This includes offering self-management skills and assessing needs of caregivers, assisting caregivers in coordinating patient clinician visits, and documenting patient and caregiver goals of care.

Tax Relief for Long Term Care Act (HR 6237) 2008

Representative Joe Courtney (D-CT) - Ways and Means Committee; 0 cosponsors

This provided a tax credit for long term care insurance premiums and general caregiver support for family members with long term care needs. It phased in a maximum credit amount of \$3,000 over four years and reduced credit amount for taxpayers with an adjusted gross income over \$75,000.

Comprehensive Long-Term Care Support Act (HR 7095) 2006, 2008

Rep. Stephanie Herseth (D-SD) - Ways & Means and Education & Labor Committee; 1 cosponsor

This bill provided a phased in deduction plan for taxpayers with long term care premiums and allowed for long term insurance as a benefit under tax qualified cafeteria plans and flexible spending arrangements.

Caregiver Assistance and Relief Effort (CARE) Act (S 2121) 2007

Senator Robert Menendez (D-NJ) – Finance Committee; 2 cosponsors

This bill allowed for a caregiver tax credit, a tax deduction for long term care insurance premiums, and long term insurance consumer protections.

Tax Relief for Working Caregivers Act (HR 1911) 2007

Rep. Joe Donnelly (D-IN) – House Ways and Means Committee; 8 cosponsors

This act expands the Child and Dependent Tax Credit for taxpayers who pay caregiving expenses for parents or grandparents who do not reside with them.

Living Well with Fatal and Chronic Illness Act (HR 4249) 2005

Representative James Oberstar (D-MN) - Ways and Means Committee; 1 cosponsor

This bill directs the Secretary to execute research, demonstration, and education programs in regards to fatal chronic illnesses and end-of-life care. It also asks the Director of Secretary of Veterans Affairs to implement programs to enhance delivery of health & support services to patients with fatal chronic illnesses.

Comments

There remains an urgent need for increased family caregiving support legislation. The value of family caregiver services is estimated at \$450 billion annually in 2009 - more than total Medicaid spending in 2009 and more than twice total paid long-term services and supports, regardless of payer source (\$203 billion in 2009). Nevertheless, the caregiver median income is lower than in non-caregiving families and caregivers' health statuses are often compromised.

An abundance of proposals exist that could provide further support for caregivers. Overall, these proposals would provide caregivers with education, resources, and increased tax preferences.

Section 3

Professional Education and Workforce Development

Section 3

Professional Education and Workforce Development

Overview

Professional training in the area of advanced illness has received substantial attention in recent years, particularly as it relates to palliative care. For instance, as a part of his Trajectories and Palliation Study (TAPS) project, Dr. Karl Lorenz of RAND examined the use of palliative services among Medicare beneficiaries living with serious, chronic, eventually fatal illness. He found that among providers, the lack of training and education in palliative and hospice care was a recurring problem. Additionally, as reported by the Center to Advance Palliative Care and the National Palliative Care Research Center, only 78 allopathic and osteopathic sub-specialty training fellowships programs were established as of 2010. This leaves approximately one palliative care physician for every 1,200 persons living with a prolonged or chronic illness. Thus, there remains a pressing need for comprehensive, in-depth palliative care training among the wider population of physicians.

Professional Education and Workforce Development Reform Informal Proposals

1. Professional education

- Award federal grants and contracts to states for establishing palliative care and hospice education programming;
- Provide mandatory Education in Palliative and End-of-Life Care (EPEC) training for physicians and End-of-Life Nursing Education Consortium (ELNEC) training for nurses and expand training initiatives for social workers, psychologists, and direct care workers.
- Establish medical school guidelines for a minimum amount of end-of-life training as a requirement for obtaining a degree in both allopathic and osteopathic medicine;
- Exempt palliative medicine fellowship training from Medicare graduate medical education caps.

2. Workforce development & team-based care

- Develop workforce training grants that promote symptom assessment and management and update and expand the 9/02 HRSA report, “The Supply, Demand and Use of Palliative Care Physicians in the US;”
- Establish within the National Health Service Corps a National Geriatric and Palliative Care Services Corps or a National Caregiver Corps;
- Direct the Health Resources and Services Administration to identify health professional shortage areas (HPSAs) within geriatric care;
- Provide dementia specific training for all direct care workers in long-term care (LTC) facilities (this issue was partially addressed by the Affordable Care Act (ACA)’s “Dementia and Abuse Prevention Training” that provides for inclusion of dementia management and patient abuse training for the initial 75 hours of nursing aide training);
- Offer incentives for individuals to train for, seek, and maintain employment providing direct care across all care settings;
- Focus on developing a team-based system of care to achieve best clinical outcomes. Training and education in palliative care should commensurate with education and experience in a physician-led, collaborative setting.

3. Financial incentives

- Make grants to care facilities to: (1) offer continuing training and varying levels of certification to employees who provide direct care to LTC facility residents and (2) provide bonuses or other benefits to employees who achieve certification;
- Create a LTC facility worker employment tax credit.

Formal Professional Education and Workforce Development Reform Proposals

Palliative Care and Hospice Education and Training Act (S 641 and HR 1339) 2012, 2013

Senator Ronald Wyden (D-OR) - Health, Education, Labor, and Pension Committee; 3 cosponsors

Representative Eliot Engel (D-NY) – Ways and Means Committee; 25 cosponsors

This bill would award grants or contracts to establish Palliative Care and Hospice Education centers, schools, teaching hospitals, and support the Graduate Medical Education (GME) programs to teach palliative care medicine and distribute academic career awards to advanced illness practitioners.

Patient Centered Quality Care for Life Act (HR 1666) 2013

Representative Emanuel Cleaver (D-MO) – Ways and Means Committee; 13 cosponsors

This bill would direct the Secretary to organize a Patient-Centered Health Care and Quality of Life Stakeholder Summit to (1) identify barriers to providing patient-centered health care and integrating palliative care & symptom management and (2) developing solutions for quality of life issues for the growing aging population. It would also establish a workforce training initiative to ensure a sufficient number of health professionals is available to care for highest risk and complex patients.

Retooling the Health Care Workforce for an Aging America Act (S 3730)**2008***Senator Hebert Kohl (D-WI) - Health, Education, Labor, and Pension Committee; 0 cosponsors*

This act requires DHHS to expand training in geriatrics & long term care management and requires an analysis of the long-term care workforce. It provides family caregiver training materials, creates a national resource center, and develops a panel of long-term care workforce experts.

Palliative Care Training Act (S 1000)**2005***Senator Ronald Wyden (D-OR) – Health, Education, Labor, and Pensions Committee; 0 cosponsors*

This act directs the Secretary to establish a program providing hospice and palliative care academic career awards and requires the awardee to offer training in hospice care and palliative medicine.

Comments

Beyond furthering the use of EPEC and ELNEC training, most professional education proposals are generic. However, among palliative treatments, pain management has received considerable attention since it is widely under-managed. For example, the 2011 Institute of Medicine (IOM) report, “Relieving Pain in America” called pain under treatment a “public health crisis.” Unrelieved pain accounts for a substantial number of office visits and is a major cause of disability and poor quality of life. The IOM recommended that DHHS develop a comprehensive plan with specific goals, actions and time frames to address this issue. The Center for Disease Control (CDC) estimated that, among pharmaceutical drug overdoses, 75 percent were caused by opioid analgesics (e.g., oxycodone) misuse.

Overall, the national needs focus on the rising “tsunami” of older Americans (10,000+ enter Medicare eligibility age per day), and point to the lack of knowledge and experience in person-and family centered management of chronic illness in this ever-increasing population. It’s clear that palliative care practitioners will never be able to absorb the current and approaching demands, thus current practitioners will need continuing professional education to address the national needs.

In addition, there is a great need to develop and expand team-based approaches to long-term care. At the AAMC’s annual Physician Workforce Research Conference in 2011, speakers noted the lack of available research on team-based care practices and urged doctors to “retrofit” their skills to work in greater collaboration, offer a wider range of care services, and adapt to changing care environments and upcoming provider shortages.

Section 4

Payment Reform and Quality Measurement

Section 4

Payment Reform and Quality Measurement

Overview

Payment and regulatory system reform continues to be one of the most engaging topics in health care policy circles today. The ACA put in place several demonstration projects to test themes, constructs, and specific proposals aimed at shifting the paradigm of health care delivery in America to achieve what this administration refers to as the “triple aim”: better population health, better health outcomes, and lower costs. While the ACA and these individual projects carry with them varying degrees of political controversy and tension, there is broad and deep consensus across the board that the current trajectory of our health care delivery system, especially for individuals facing advanced illness, is wholly unsustainable. Furthermore there is also broad consensus that to appropriately address the challenges we will need to shift to some type of value-based reimbursement, focusing on rewarding quality over quantity, and promoting some type of shared-accountability and shared-investment from consumers, payers, providers, and other stakeholders.

In theory, the predominant models of advanced illness care delivery that are being tested all fit well into this approach. While the demonstration projects and various initiatives do provide some hint of the direction of delivery system reform, there does not seem to be a predominant legal and regulatory construct that is emerging. Accountable Care Organizations, Patient-Centered Medical Homes, bundled payments for episodes of care, and other efforts including those emerging through the Medicare/Medicaid dually eligible integration projects all show promise. For example, the medical home is a model that shows great promise to achieving primary care excellence so that care is received in the right place, at the right time, and in the manner that best suits a patient’s needs, all aspects that seem ideally suited to ensuring high-quality and patient-centric advanced and palliative care. However, without certainty that the medical home model, or ACO or any of the others, will become predominant, it is difficult for stakeholders to develop and implement standardized models of care that will be sustainable over the long run.

In addition to payment and regulatory reform, hospice and palliative care quality measurement and reporting is developing from its nascent stage. The ACA's Hospice Quality Reporting Program (Section 3004) requires Medicare-certified hospices to begin reporting quality data in FY 2013. For FY 2014, the first year reporting will be tied to reimbursement and hospices will report on just two measures: whether (1) pain upon admission was brought to a comfortable level within 48 hours and (2) whether the hospice is participating in a quality assessment and performance improvement program including at least three quality indicators related to patient care. CMS will add to these two measures year over year. For FY 2015, CMS has already noted preliminary interest in these five measures:

1. Percentage of hospice or palliative care patients who were screened for pain during initial admission to hospice & palliative care centers. (NQF measure 1634)
2. Percentage of hospice or palliative care patients who screened positive for pain and received a subsequent clinical assessment within 24 hours of screening. (NQF measure 1637)
3. Percentage of patients who screened positive for dyspnea who received treatment within 24 hours of screening. (NQF measure 1638).
4. Percentage of hospice or palliative care patients who were screened for dyspnea during the hospice admission evaluation/palliative care initial encounter. (NQF measure 1639)
5. A composite measure related to family evaluation of hospice care via the Family Evaluation of Hospice Care survey. (NQF measure 0208)

CMS is also developing a family experience of hospice care instrument for submission to the Consumer Assessment of Healthcare Providers and Systems (CAHPS) and National Quality Forum (NQF). Medicare's Hospital Compare has expanded to include nursing homes and is expected to reach hospice. In the Physician Quality Reporting System (PQRS), measures include: advance directive/surrogacy, pain assessment and follow-up, pain intensity, and pain plan for medical oncology for radiation therapy.

The NQF released a June 2012 report in collaboration with the Measurement Applications Partnership (MAP) entitled "Performance Measurement Coordination Strategy for Hospice and Palliative Care" to assess quality of care through approximately 25 measures in six key categories. These measures examined both clinical as well as administrative procedures and sought to identify patient and family centered, comprehensive care practices.

Measures included hospice-specific as well as palliative care-specific assessments and ranged across disease types.

- Access/availability of services – This examines access to both hospice and palliative services across care settings, availability of a 24-hour healthcare team, spiritual care services, and timeliness of care.
- Patient and family-centered care-- This focuses on caregiver education and assesses standards of comprehensive care by examining psychological/psychiatric, religious, and physical support systems.
- Goals and care planning – This examines advance care planning, shared decision-making, and implementation standards of patient, family, and caregiver goals.
- Care coordination – This assesses provider communication and sharing of medical records (including ACDs) across care settings.
- Provider competency – This focuses on medical education and training.
- Appropriateness/affordable care – This assesses the quality and affordability of care and examines unwanted hospital treatments and admissions.

In 2012, the NQF- owned Measure Applications Partnership (MAP) submitted a report to DHHS providing recommendations for new quality reporting programs. These reports focused on developing measures for: (1) assessing patient quality of life, (2) evaluating pain and symptom management, and (3) examining adherence to patient guidelines and wishes for patients in hospices and SNFs. The assessments were designed to be meaningful quality measures for patients and families and provide useful information on unwanted medical procedures and hospital trips. NQF has stated it intends to revisit hospice and palliative care measures in 2014. Lastly, the AHRQ has also adopted NQF-endorsed measures to assess patient depression that can also be used by long term care providers.

Informal Payment Reform & Quality Measurement Reform Proposals

1. Quality Assessments

- Require development of quality measures for each relevant provider setting;
- Designate an entity to develop requirements, standards, and procedures for accreditation of hospital-based palliative care programs;
- Authorize HHS to develop specific quality measures pertaining to planning services such as linking patient goals to treatment received and outcomes;
- Require decedent surveys on advanced care;
- Accelerate palliative care quality improvement initiatives throughout the acute and post-acute service areas;
- Require “look back” surveys on patients with ACD and POLST to see if wishes were honored.

2. Coverage Expansion

- Create a Medicare palliative care benefit (for instance, allowing hospice services for patients without the six month diagnostic and forgoing of curative care);
- Allow for non-traditional palliative care services such as radiation;
- Improve the coordination between acute care services and long-term services and support (LTSS) and improve reimbursement for LTSS;
- Provide Medicare Part B coverage of geriatric assessments and chronic care coordination services for eligible individuals;
- Require hospice be a Medicaid and CHIP benefit;
- Ensure all ACA coordinated care/accountable care/medical home & innovate care initiatives include palliative care/ACP/POLST components;
- Encourage nursing homes to establish palliative care and hospice units and cooperate more fully with existing hospice providers;
- Include bereavement counseling under the existing Medicare psychiatric benefit;

3. Administrative

- Instruct hospitals to develop “compassionate non-discharge policies” when death is imminent but the physician and family wish to have the patient remain in the hospital;
- Provide incentives to hospitals for accreditation and certification in hospice and palliative care;
- Model palliative care policy scenarios regarding pay for performance schemes similar to the Premier demonstration. The CMS/ Premier Hospital Quality Incentive Demonstration (HQID) project assessed whether financial incentives could incentivize hospitals to outperform others. It also examined the impact of utilizing clinical process and outcomes measures in hospitals on secondary outcomes – readmissions and additional costs;
- Direct the Secretary to study the extent to which the actual care plan reflects assessments in hospitals, SNFs, HH and hospice;
- Require all PROs (Professional Review Organizations) include at least one palliative care expert;
- Develop more stringent metrics for pain management and control;
- Provide funding for PROs to undertake quality assurance measures to ensure all caregivers honor ACDs and deny coverage if not properly adhered to;
- Add a palliative care expert to the CMS Practicing Physicians Advisory Council;
- Require that all CMS advisory committees include physicians to evaluate the credentials of palliative care experts;
- Direct CMS to revise MDS to ensure nursing home deaths are judged against the appropriate denominator of residents;
- Modify Medicare Conditions of Participation to create an environment where palliative care is widely understood and practiced;
- Alter the Medicare carrier manual to acknowledge that concurrent care by two members of the same specialty is appropriate for palliative care treatments.

Formal Payment Reform and Quality Measurement Proposals**Care Planning Act (S 1439) 2013***Senator Mark Warner (D-VA) - Finance Committee; 1 cosponsor*

Beyond providing for a Medicare and Medicaid planning services benefit, this act requires CMS to conduct a five-year “advanced illness coordination services” (AICS) demonstration project. AICS would be developed for Medicare beneficiaries with advanced cancer, Alzheimer’s, late-stage neuromuscular disease, late-stage diabetes, end-stage organ failure, or with two or more ADLs. The AICS would assess the patient’s limitations, identify formal and informal supports, provide medication review and management and in-home support services for the patient and family caregivers, offer 24-hour emergency support, and coordinate care across health and social service systems.

Senior Navigation and Planning Act (S 3684) 2012*Senator Mark Warner (D-VA) – Finance Committee; 0 cosponsors*

This bill allows a hospice to provide care for individuals diagnosed with a life expectancy of 18 months.

Improving Dementia Care Treatment for Older Adults Act (S 3604) 2012*Senator Hebert Kohl (D-WI) – Finance Committee; 2 cosponsors*

This bill required higher quality education programming for medication prescribers and directed DHHS to develop a standardized protocol for skilled nursing facilities (SNFs) to obtain informed consent for the use of antipsychotics. It also required both the Nursing Home Compare website and the five star quality rating system to include a measure of the utilization of antipsychotics. In addition, the bill requested the IOM to study the appropriate prescribing of anti-psychotics.

National Healthcare Quality Act (S 966, HR 2252) 2009*Senator John D. Rockefeller (D-WV) – Finance Committee; 1 cosponsor**Representative Diana DeGette (D-CO) - Ways and Means Committee; 0 cosponsors*

This act would have created a White House Office of National Health Care Quality Improvement that would determine national priorities for improving health care quality as well as distribute an annual report card. It also would have created a National Quality Resource Center to assist health care providers.

Senior Navigation and Planning Act (S 1263, HR 3172) 2009

Senator Mark Warner (D-VA) – Finance Committee; 0 cosponsors

Representative Tammy Baldwin (D-WI) - Ways and Means Committee; 1 cosponsor (Same as S. 3684.)

This act allows for increased Medicare & Medicaid coverage for advanced illness management, consumer education tools for creating ACDs, and a national education campaign to generate awareness regarding the advance care planning process.

Advance Planning and Compassionate Care Act (S 1150, HR 2911) 2009

Senator John D. Rockefeller (D-WV) - Finance Committee; 7 cosponsors

Representative Earl Blumenauer (D-OR) – Judiciary Committee; 3 cosponsors

This act requires concurrent - curative and palliative - treatment for children and develops a palliative care demonstration for patients not enrolled in hospice.

Preserving Access to Hospice (PATH) Act (S 2727, HR 5542) 2008

Senator James Inhofe (R-OK) - Finance Committee; 4 cosponsors

Representative John Sullivan (R-OK) - Ways and Means Committee; 14 cosponsors

This bill suspends enforcement of the hospice cap between 2005-2008 and directs MedPAC to (1) study hospice as a substitute for other acute care alternatives, (2) identify optimal stays in hospice, and (3) determine reasons behind consistently low average length of stays.

Cancer and Terminal Illness Patient Health Care Act (HR 4684) 2007

Representative Ronald Paul (R-TX) - Ways and Means Committee; 0 cosponsors

This bill waives social security tax and reduces self-employed taxes by 50 percent for employees who suffer from cancer/terminal illness or qualify as the primary care giver for a spouse, parent or child.

Medicare Hospice Demonstration Act (S 1001) 2005

Senator Ron Wyden (D-OR) - Finance Committee; 0 cosponsors

This bill creates hospice demonstration projects in three to six sites to increase the utility of hospice services.

Comments

There has been a demonstrable increased interest on a policy level in substantially payment and care delivery reform. For instance, among other provisions, the ACA provides for a demonstration project to improve care for Medicare-Medicaid beneficiaries. It creates a medical home pilot program for Medicare beneficiaries suffering from chronic illness and provides a Medicare concurrent demonstration for both curative and palliative treatments. The ACA-created CMMI has also proposed funds to improve advanced care. For example, CMMI recently announced a large-scale implementation of bundled payments for hospital and post-acute services. C-TAC member Sutter Health received \$13 million to expand its Advanced Illness Management (AIM) program. In addition, the PCORI is also awarding money for advanced care. During its May 2013 awards, Kaiser Foundation Research Institute was given funds to develop better chronic care for patients via interactive uses of personal health records. Several C-TAC members are pursuing additional funding to further test the advanced care delivery model via CMMI funding.

MedPAC has too been increasingly active in addressing advanced care via its responsibility to recommend to the Congress Medicare payment reforms. This includes bundling acute and post acute payments to improve care coordination and continuity. MedPAC has also discussed better leveraging federally qualified health centers (FQHCs) and community health centers (CHCs) to improve Medicare and Medicaid care coordination and improve Long-term Services and Supports (LTSS) by re-balancing Home and Community Based Services waivers.

One of the most effective provider networks in delivering quality advanced illness care is the VA. The VA's Comprehensive End of Life Initiative (CELC), launched in 2009, has measurably improved veterans' access to palliative care services. For instance, per the VA's 2011 Hospice and Palliative Care Annual Report, 73% of all inpatient decedents received palliative care services (versus 47% in 2008). The PROMISE (Performance Reporting and Outcomes Measurement to Improve the Standard of care at End of life) Center compliments CELC by coordinating quantitative and qualitative measurement of VA end of life care.

Next, as mentioned above, quality measure development and use - particularly in hospice care - is in its early stages. Generally what we see here is a high reliance on process and structural measures. As noted, quality measurement of hospice and palliative care is in its' early stages. Typically, early measure development in most domains does start with process and structural measures. These measures are still important due to the variability of performance noted in the endorsement process, i.e. there is plenty of room for improvement. Outcome measures are more difficult to develop, especially for end-of-life care. The direction should be to develop patient/caregiver reported outcomes, such as, satisfaction with pain control, discussion and understanding of care plan, respecting patient/caregiver end of life requests, etc.. Objective outcomes such as pain control and dyspnea control are fraught with difficulties, but could also be measured through patient/caregiver reported outcomes. Outcomes could be short term (within 1-2 weeks of entering hospice care) or long term (perhaps after the patient has expired). Longer-term measures might include resource use (e.g., no curative level treatment with two weeks of death), site of service (e.g., place of expiration), and respecting advanced directive regarding use of extraordinary measures. Some overall objective measures could include hospice election rate, inpatient and ICU days associated with advanced illness, and use of pain medications.

Section 5

Research

Section 5

Research

Overview

Multiple proposals exist to further research in advanced illness care either through Congressional mandate or via regulatory reform. The first category of research proposals, process & outcome measures, investigates current standards in palliative treatments and end-of-life care. Priorities include analyzing critical care workforce shortages, establishing palliative care research agendas, and creating national centers to promote end-of-life care issues.

The clinical research proposals examine specific advanced illness and disease conditions. A 2009 study cosponsored by the National Alliance for Caregiving & AARP reported that, among a sample of 1,000 caregivers surveyed, the top ten problems or illnesses of care recipients included advanced stages of Alzheimer's, cancer, and heart disease among other conditions. The following pieces of legislation seek to improve patient health outcomes by expanding diagnostic services, studying disease progression, examining treatment side effects, and providing better targeted therapeutic strategies for minority populations.

Informal Proposals

1. Have CMS undertake a comprehensive review of all agency policies that affect end-of-life care;
2. Analyze how an episode of care is defined for patients with chronic disease, examine palliative care requirements, and determine how to incentivize palliative care within a capitated payment model.
3. Require DHHS to conduct a mortality follow back survey including questions concerning advanced care planning, hospice, and palliative care utilization;
4. Require the Agency for Healthcare Research & Quality (AHRQ) to develop a comprehensive and specific palliative care research agenda;
5. Establish within DHHS an End-of-Life Care Advisory Board;
6. Establish within the NIH a National Center on Palliative and End-of-Life Care.

Formal Research Proposals – Process and Outcome Measures**Critical Care Assessment and Improvement Act (HR 2651)****2013**

Representative Erik Paulsen (R-MN)- Ways & Means and Energy & Commerce; 2 cosponsors

This proposal would authorize the IOM to (1) analyze the current state of critical care services, (2) require HRSA to update its 2006 study on critical care workforce shortages, (3) create a Critical Care Coordinating Council with NIH to coordinate related research activities, and (4) authorize CMS to conduct a demonstration program to improve critical care.

Advance Planning and Compassionate Care Act (S 1150, HR 2911)**2009**

Senator Mark Warner (D-VA) – Finance Committee; 6 cosponsors

Representative Earl Blumenauer (D-OR) – Ways and Means Committee; 3 cosponsors

This bill would develop core end-of-life quality measures across each relevant provider setting, direct CMS to create patient satisfaction surveys, and establish a national center on palliative and end of life care at the NIH.

Formal Proposals – Clinical Research

Making Investments Now for Dementia (HR 1619) 2013

Rep. Michael Burgess (R-TX) – Energy & Commerce; 8 cosponsors

This bill directs the Secretary of the Treasury to issue bonds to fund Alzheimer’s research as well as authorizes the Director of NIH to expand research initiatives on the disease.

Health Outcomes, Planning, and Education for Alzheimer’s Act 2013

Representative Edward Markey; Energy & Commerce; 136 cosponsors

This bill expands Medicare coverage to include more comprehensive diagnostic services for Alzheimer’s and other forms of dementia to provide better outcomes of care.

Improving Cancer Treatment Education Act (HR 1661) 2013

Representative Steve Israel (D-NY) – Energy & Commerce and Ways & Means; 27 cosponsors

This bill extends Medicare coverage to include comprehensive cancer treatment education services. It also requires the Director of NIH to (1) expand research programs to study symptom management & treatment and (2) examine the use of nursing interventions to pacify treatment side effects.

National Pediatric Research Network Act (HR 225) 2013

Representative Lois Capps (D-CA) - Health, Education, Labor, and Pensions Committee; 10 cosponsors

This bill creates a national pediatric research network under the NIH and includes support for up to five years.

- Alzheimer’s Breakthrough Act (HR 1897)** **2011**
Rep. Christopher Smith (R-NJ) –Energy & Commerce Committee; 135 cosponsors
 This bill requires the Director of NIH to develop a strategic research plan to develop better therapeutic outcomes for individuals at risk for Alzheimer’s disease. It also expands the Alzheimer’s Disease Center program to facilitate the translation of research into clinical measures.
- Acquired Bone Marrow Failure Disease Research and Treatment Act (HR 1230)** **2010**
Rep. Doris Matsui (D-CA) – Health, Education, Labor, and Pension Committee; 62 cosponsors
 This bill requires DHHS to research bone marrow failure diseases, work with the C. W. Bill Young Cell Transplantation Program, and improve outreach to targeted minority communities affected by the disease.
- HEART for Women Act (S 424, HR 1032)** **2009**
Sen. Deborah Stabenow (D-MI) – Health, Education, Labor, and Pensions Committee; 44 cosponsors
Representative Lois Capps (D-CA) - Energy and Commerce Committee; 167 cosponsors
 This bill (1) expands funding for FY’12-FY’16 for preventive health services and medical treatments for women with breast or cervical cancer, (2) requires DHHS to report to Congress on the quality of care for women with heart disease, stroke and other cardiovascular diseases, and (3) directs the GAO to report the extent to which clinical studies follow FDA guidelines relative to sex, age and racial subgroups.
- Children’s Compassionate Care Act (HR 5192)** **2007**
Representative Deborah Pryce (R-OH) -Ways and Means Committee; 1 cosponsor
 This bill sponsors HRSA and NIH to award grants for pediatric palliative care training. It provides funding for research examining pediatric pain and symptom management and organizes symposiums on pediatric palliative care.

Comments

There have been a couple of private sector initiated research efforts that examine approaches to advanced illness care. Despite the wealth of studies and data analysis supporting the effectiveness of particular components of advanced illness care, there is a lack of standardized approaches to data collection and analytics to study more comprehensive, system-based interventions. Several C-TAC members are engaged in such efforts, but there needs to be a central repository of information to analyze and compare studies. This will help maximize learning and improve the dissemination of information. In some senses, CMMI is playing that role, but the information learned from their projects has not been widely distributed. Lastly, many of the above proposals examining clinical research have garnered numerous cosponsors and received significant bipartisan support. It is essential to continue promoting these pieces of legislation in order to enhance care delivery and improve health outcomes for the advanced illness population.

Conclusion

It is our hope that stakeholders and policymakers alike will use this report as a comprehensive tool to assess the current landscape of policy options, pinpoint gaps or shortcomings in recent proposals, and identify those provisions that promote and sustain effective, best-practice models of care. This policy review examines seven key areas within the scope of advanced illness: (1) Advance Care Planning & Advance Directives, (2) Consumer & Family Caregiver Education and Support, (3) Professional Education and Workforce Development, (4) Payment Reform and Quality Measurement, and (5) Research. Within these topics, Advance Care Planning & Advance Directives has accumulated the highest number of reform proposals compared to areas in Health Information Technology, Professional Education and Workforce Development, and Quality Measures. In addition, few proposals focus on issues relating to care coordination & continuity in long-term care settings or address patient populations suffering from comorbidities and functional limitations. Lastly, many research and quality initiatives rely on Congressional authorizations that are continually dependent on future appropriations.

Although we do not address the implementation and logistical details of these policy proposals, we do hope to spark necessary conversations regarding advanced illness care, management, and treatment options. These discussions can be further enhanced through the sharing of personal stories of family members, friends, and caregivers supporting loved ones with advanced illness. Together, initiating and sustaining this dialogue is the first step toward building comprehensive, high-impact bipartisan reform that will benefit an extended network of advanced illness patients, families, and providers. Moving forward, we welcome any comments or insight on this preliminary outline of proposals. It is our goal to help promote a family-centered and patient-centered system of advanced care that is reflective of one's dignity and wishes and ensures a high level of quality care.

Glossary of Terms

Accountable Care Organizations (ACOs) – Groups of health care providers who volunteer to give highly coordinated and integrated care to patients.

Agency for Healthcare Research & Quality (AHRQ) – An agency within the Department of Health & Human Services that promotes the quality, safety, efficiency, and effectiveness of health care. It gathers research findings and informs providers and policymakers to develop a better standard of care.

Consumer Assessment of Health care Providers and Systems (CAPHS) – An initiative by AHRQ to assess consumers' experiences with health care. CAPHS survey questions include topics such as access to health care services and health care provider communication skills.

Children's Health Insurance Program (CHIP) – A program that provides health coverage to children whose families who are illegible for Medicaid but who cannot afford private coverage.

Center for Medicare and Medicaid Innovation (CMMI) – A program that helps develop and test new health care payment and delivery models.

Centers for Medicare & Medicaid Services (CMS) – An agency that administers Medicare, Medicaid, and CHIP.

End of Life Nursing Consortium (ELNEC) – A project that supports national education to improve the quality of palliative care.

Education in Palliative and End-of-life Care (EPEC) – An organization that enhances the palliative care training of medical professionals. Its curriculum includes training in communication, ethical decision-making, psychosocial considerations, and symptom management.

Full Time Equivalent (FTE) – A unit that describes the ratio of total paid hours in a period by the number of working hours in that time.

Government Accountability Office (GAO) – An agency that investigates the receipt and payment of public funds.

Health Professional Shortage Areas (HPSAs) – Geographic, demographic, or institutional areas that experience a shortage of primary medical care or general health services.

Health Resources and Services Administration (HRSA) – An agency that improves health care access for those who are medically vulnerable, uninsured, or isolated.

Indian Health Services (IHS) – An agency that provides health care to Native American or Alaskan Native peoples.

National Quality Measures (NQM) – Measures used to quantify and assess health care processes, outcomes, patient perceptions, and organizational structure.

Physician Orders for Life Sustaining Treatment (POLST) – A form that states the type of end-of-life care patients want to receive towards the end of their lives. A POLST document, rather than a standard ACD, is universally recognized by physicians, paramedics and first responders. It is typically issued for patients with terminal illness or progressive disease.

Physician Quality Reporting System (PQRS) - A program that provides incentive payments to encourage health care professionals to report accurate information about the quality of care.

Skilled Nursing Facility (SNF) – A type of residential care that is often funded by Medicare for Part A beneficiaries.
VA Promise – A program that uses personal interviews with patient family members as well as medical record reviews to assess the quality of end-of-life care for veterans.

VA Promise – A program that uses personal interviews with patient family members as well as medical record reviews to assess the quality of end-of-life care for veterans.