

# Generations

Journal of the American Society on Aging

## Reforming Advanced Illness and End-of-Life Care: The Way Forward



Closing the gap  
in end-of-life care

The right care, at the right  
time: a personal reflection

The best and worst  
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# Generations

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inside **generations**

# Reforming Advanced Illness and End-of-Life Care: The Way Forward

## 4 Our Guest Editors

By Bill Novelli and Raca Banerjee

---

the current landscape

## 6 Closing the Care Gap

By Bill Novelli and Raca Banerjee

## 10 Understanding Cultural Gaps and Disparities in Advanced Illness Care

Interview by Marian Grant

## 16 Building the Road Ahead: Reflections on the C-TAC National Summits

By Jon Broyles

## 21 Supporting the Patient Voice: Building the Foundation of Shared Decision-Making

By Patricia Bomba

## 31 Advance Care Planning: Ensuring Patients' Preferences Govern the Care They Receive

By Brad Stuart, Angelo Volandes, and Benjamin W. Moulton

---

changing the culture of care

## 37 Aid in Dying: A Consideration of Two Perspectives

By Bill Novelli and Raca Banerjee

## 39 Medical Aid in Dying: The Cornerstone of Patient-Centered Care

By Barbara Coombs Lee and David Grube

## 42 Death by Lethal Prescription: A Right for Older People—or Their Duty?

By Burke Balch

## 47 My Life, My Story: A Personal Experience with the Right Care, at the Right Time

By Amy Berman

## 50 Caregiving at the End of Life: The Challenges for Family Caregivers

By Barbara A. Given and Susan C. Reinhard

## 58 Lessons from the Hospice Benefit for Advanced Illness Care

By Perry G. Fine and Malene S. Davis

## 68 A Prescription for Population-Based Palliative Care Education

By Jason A. Webb and David Casarett

## 74 The Changing Landscape of Palliative Care

By Diane E. Meier and Brynn Bowman

## 81 Hope for Persons with Dementia: Why Comfort Matters

By Tena Alonzo

## 86 Next-Generation Quality Measurement to Support Improvement in Advanced Illness and End-of-Life Care

By Helen Burstin and Karen Johnson

---

policy actions for the future

## 94 Policy and Politics to Drive Change in End-of-Life Care: Assessing the Best and Worst Places to Die in America

By Andrew L. MacPherson and Ravi B. Parikh

## 102 Patient Preferences, Policy, and POLST

By Judy Thomas and Charles Sabatino

## 110 Advanced Illness Care: Driving the Movement Forward

By Bill Novelli and Raca Banerjee

# Our Guest Editors

## Reforming Advanced Illness and End-of-Life Care: Yes We Can

Advanced illness care is a big, tough, deeply engrained problem. But it's not intractable.

BILL NOVELLI



The way we die in America has evolved into an overly clinical, heavily medicalized, and fraught process that too often ends in a hospital room. **Bill Novelli** and **Raca Banerjee**, our Guest Editors for this Spring 2017 issue of *Generations*, are making it their life's work to change this scenario. Their level of commitment to improving care at the end of life—to make it person-

centered and ensure that such care honors dignity and individual preference—shines through in this issue of *Generations*. It is our hope that through their work, and that of other contributors to this journal, better solutions are now at hand for how our country's healthcare system treats chronic illness and how Americans face death.

As the co-chair of the Coalition to Transform Advanced Care (C-TAC), Novelli is “deeply engaged” in the C-TAC alliance of almost 140 patient and consumer advocacy groups, healthcare professionals and providers, private-sector stakeholders, faith-based organizations, and healthcare payers. C-TAC “works to ensure that all those 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.”

Novelli believes that “advanced illness and end-of-life care [are] a critical part of the life process, and greatly in need of reform.” The issue is deeply personal for both Guest Editors, as they realize that everyone has, as Banerjee says, “a parent, relative, friend, or loved one who has experienced serious illness.”

Banerjee previously served as the Policy and Clinical Models Program Manager for C-TAC, building policy expertise on a range of issues, including Medicare and Medicaid reform and delivery system innovation. She now volunteers in her spare time with Aging 2.0, a global platform that supports local start-ups with creative ideas for changing the way we care for elders, where she promotes innovative technologies and care approaches that can improve patient satisfaction and tailor care at the individual level. At C-TAC, Banerjee helped to design, publish, and promote a federal policy agenda to improve advanced illness care, which received a positive reception from health systems, payers, employers, patient groups, purchasers, and others. She is quick to credit the team she worked with on this issue, and relished “forming a common mission and vision together.”

In addition to his work with C-TAC, Novelli founded and oversees the Global Social Enterprise Initiative, and is a Distinguished Professor of the Practice,

both at Georgetown University's McDonough School of Business. Prior to that he served as CEO of AARP, as president of the Campaign for Tobacco-Free Kids, as executive vice president of CARE (the international relief and development organization), and was co-founder and president of Porter Novelli, one of the world's largest public relations firms.

He is proudest of helping to get prescription drugs into Medicare through the Medicare Modernization Act, fighting the tobacco industry and curbing youth and adult tobacco use, and helping to protect Social Security from privatization.

Seeing his work as far from finished, Novelli's "career goal is to make significant contributions to solving major social problems." Advanced illness care is "this problem that's big, tough, and deeply ingrained in our culture. But it's certainly not intractable," he says, citing as proof his favorite saying (attributed to Danish mathematician and poet Piet Hein), "Problems worthy of attack, prove their worth by fighting back."

"That's what we have here. And we can reform and solve this problem," Novelli adds.

"For me, the challenge is timing," says Banerjee. "We need to act now—and fast! If [Americans] don't come together to improve the way we care for older adults, we risk denying our [elders] the high-quality, comprehensive care they want and deserve."

"As Americans, we all place a high value on individual choice, freedom, and autonomy. Why shouldn't that

apply to the care experience—especially as we get older?" asks Banerjee. "Our goals, values, and preferences define us and should form the cornerstone of the kind of treatments we receive. That kind of thinking needs to spread throughout our delivery system."

Novelli sees the future of transforming advanced illness and end-of-life care as bright—one that puts patients and their families at the center of treatment choices and decisions—a future that clinicians and healthcare entities are now beginning to understand. He knows the baby boomers will not accept their parents' style of care (which he heard one member of that generation call "assault and battery care"), but he also knows advocacy is still needed to educate consumers, support new policies, and promote best practices.

Asked to speak at a college reunion, and invited to choose any topic, Novelli told organizers he'd be talking about "dying better in America." "Great," they said, "We'll get two or three people to come to that."

More than a hundred people showed up for the event, and organizers scrambled to find additional chairs to accommodate the crowd. "People aren't really afraid of the subject," says Novelli.

"What they want is choice—choice and control. And that's where we're going with this essential part of life."

—Alison Biggar and Alison Hood

**As Americans, we all place a high value on individual choice, freedom, and autonomy; why shouldn't that apply to the care experience—especially as we get older?**

RACA BANERJEE



# Closing the Care Gap

By Bill Novelli  
and Raca Banerjee

America is still finding its way to patient-centered, high-quality end-of-life care.

As Guest Editors of this issue of *Generations*, we are pleased to introduce the Spring 2017 edition of the journal, which is dedicated to one of the most important issues affecting our nation's future: ensuring that all Americans with advanced illness receive comprehensive, high-quality, and person- and family-centered care that is consistent with their goals and values, and honors their dignity.

Anyone, even children, can be seriously ill, but people with advanced illness—i.e., one or more chronic conditions leading to irreversible decline in health and function—deserve special attention (Coalition to Transform Advanced Care [C-TAC]/AHIP Foundation, 2015). As many people with serious illness are expected to recover, for them, aggressive treatment often is appropriate.

On the other hand, people with advanced illness often need help with the transition from curative treatment to excellent end-of-life care. Quality of life, not cure at any cost, becomes the goal. This transition must be guided by a

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***'We all want to be the authors of our lives.'***

patient's informed choice, established with his or her clinicians in a process of shared decision-making. Far too many patients with advanced illness never have the chance to participate in this vital process.

Most Americans with advanced illness are frail older adults. Over the next two decades, the number of people ages 65 and older will nearly double to more than 72 million, or one in five Americans (C-TAC, 2016). As the large baby boomer population continues to age (the oldest baby boomers are now age 71), our care delivery system faces a rapidly growing number of people with multiple chronic conditions and disabilities who will need high-quality care tailored to their changing physical, emotional, and spiritual needs.

Despite its many strengths, our healthcare system is ill-equipped to provide such care. Without substantial improvement, those with advanced illness are and will be at higher risk for unnecessary hospitalizations, unwanted treatments, adverse drug reactions, and conflicting medical advice—all of which can result in higher out-of-pocket costs to families and wasteful healthcare expenditures for the nation.

**→ABSTRACT** This article introduces readers to the Spring 2017 issue of *Generations*, dedicated to ensuring all Americans with advanced illness receive comprehensive, high-quality, and person- and family-centered care consistent with their goals and values. Our healthcare system is ill-equipped to provide such a comprehensive approach to care, but it is the hope that this edition of the journal provides a solid perspective on critical issues and a map of the terrain ahead. No magic solution can change the way we care for people with advanced illness, but multiple pathways exist to drive change in how we care for our sickest and most vulnerable citizens. | **key words:** *advanced illness, person- and family-centered care, care delivery system, end-of-life care*

A wide gap separates the care that individuals with advanced illness want and the treatment they receive. Research shows that most people want to spend their days in the safety and comfort of home, surrounded by family, friends, and other loved ones. They want to maintain their independence, have their pain managed, have their spiritual needs addressed, and, perhaps above all, they want to avoid impoverishing their families. Instead, they often enter the revolving door of the hospital,

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***Each health system must be approached with a flexible, personalized plan capitalizing on existing efforts to improve.***

undergoing aggressive treatments that may not prolong their lives or improve their quality of life—perhaps then dying in pain, at great cost to their families and to society (Cloud, 2000). We must close this gap.

**Reforming the Care Delivery System**

A deeper problem plagues our care delivery. Our focus on procedure-based services incentivizes siloed, fragmented care that ignores the whole person. Patients with advanced illness may be forced to navigate a complex system of post-acute settings and providers who fail to communicate with each other about the care regimen, or attend to documented care goals and preferences across sites of care. We must reform this system.

Our mission is personal. We all have stories about good clinical intentions gone awry, often involving a mother, father, spouse, grandparent, or friend. This shared experience brings us together. We all want to ensure that our loved ones' goals, values, and wishes are honored as they go through this most difficult phase of life. And this is what the people we care about want, too. As Atul Gawande wrote in his book, *Being Mortal* (2014), "We all want to be the authors of our lives."

The kind of care we need cannot just suddenly appear at the moment illness becomes advanced. Rather, it is a comprehensive approach that must be available at the onset of illness, or during diagnosis. When a person begins to develop chronic conditions, providers should carefully and honestly communicate with the patient and family about treatment options and the risks and benefits of each. They should have an informed conversation about the values, goals, and preferences of the patient and family, and those treatment options and preferences should be clearly labeled and included in the healthcare record. That record should be regularly updated and shared with others who are part of the patient's healthcare team, including specialists, to ensure seamless integration of care. Health systems should work with community- and faith-based organizations to coordinate clinical and community services. These are all key principles of excellent advanced illness care.

We need widespread implementation of care models based upon these principles. Studies note significant variations across the United States in the quality, access, choice, and cost of care for advanced illness. The Dartmouth Atlas of Healthcare has chronicled marked differences among regions in hospice use, numbers of deaths in the ICU, hospital readmission rates, and patient satisfaction (The Dartmouth Atlas of Healthcare, 2016). These differences help us focus on localities and systems that are ripe for transformation. No two health systems or communities are alike; each must be approached with a flexible, personalized plan that capitalizes on existing efforts to improve.

Accepting the growth of the aging population and the limited capacity of today's healthcare workforce will require us to train interdisciplinary care teams, as well as family caregivers, to support the unique needs of those with advanced illness. This entails introducing new kinds of training in medical and nursing schools, breaking down educational silos that interfere

with the development of clinical teams, and promoting better communication skills for clinicians so they can more effectively engage patients and families in treatment decisions.

### **Why Now Is the Time for Change**

The 2014 National Academy of Medicine (formerly the Institute of Medicine) report, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, states: “A substantial body of evidence shows that broad improvements to end-of-life care are within reach . . . improving the quality and availability of medical and social services for patients and their families could not only enhance quality of life through the end of life, but may also contribute to a more sustainable care system” (Institute of Medicine, 2014).

Regulations issued in 2016 by the Centers for Medicare & Medicaid Services (CMS) pay clinicians to hold advance-planning discussions with patients and families (CMS, 2016). This is a significant step forward, but more innovative and comprehensive reforms are needed.

Many innovators have implemented value-based approaches to care delivery, enabling payers, providers, employers, communities, and others to try new approaches to care for this population (C-TAC/AHIP Foundation, 2015). The need for higher quality, greater care coordination, and increased accountability align with policy reform goals of Republicans and Democrats alike. The new Administration in Washington has pledged to focus on health-care with an eye toward achieving Medicare and Medicaid program sustainability. This drive to contain costs is important, and can be aided by the significant savings that high-quality advanced illness care provides. Because these savings result from fully informed choice and shared decision-making, they are free of the controversy that could be generated by cutting services to vulnerable patients. As we reform and improve payment structures, keeping the patient and family at the center of

care will allow us to do the right thing, while providing immeasurable savings to families and to the nation.

The past decade has brought more focused attention to advanced illness via increased media coverage and published literature. Public perceptions are shifting. The baby boomers are

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### ***Keeping the patient and family at the center of care will allow us to do the right thing.***

likely to demand more transparency, better communication, and increased choice in treatment. Books such as Atul Gawande’s *Being Mortal*, Paul Kalanithi’s *When Breath Becomes Air*, and Angelo Volandes’s *The Conversation* provide real-life stories that have vaulted the issues of advanced illness and end-of-life care into the public consciousness (Gawande, 2014; Kalanithi, 2016; Volandes, 2015).

### **The Road Ahead to Lasting Change**

This issue of *Generations* addresses important issues regarding the way America treats its seriously ill. Section One, “The Current Landscape,” covers the care continuum and understanding cultural differences, policy issues at the federal level, and perspectives from three national summits convened by C-TAC.

Section Two, “Changing the Culture of Care,” examines patient and family roles in sharing treatment decisions with the clinician team, advance care planning and advance directives, living with advanced illness, the challenges of caregiving, lessons from decades of the hospice benefit, public education and engagement, the state of play with regard to palliative care, and the challenges of dementia. Both sides of the debate over aid in dying, now legal in many states and under consideration in others, also are examined.

And finally, Section Three, “Policy Actions for the Future,” addresses the need for im-

proved quality metrics and moving to value-based care, advocating for effective federal legislation, and building strong state policies. The issue ends with a call to action: the next steps, the urgency, and the opportunity to drive this movement forward.

## Conclusion

A great deal of work, much of it by authors of the articles in this issue, has already been accomplished in the effort to improve advanced illness care. What was recently only a dream has now become a movement. However, there is still much more to be done. It is our hope that this issue of *Generations* provides both a solid

perspective on critical issues and a map of the terrain ahead. No magic solution can change the way we care for people with advanced illness. But multiple pathways beckon us forward to drive change in how we care for some of our sickest and most vulnerable citizens. 

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*Bill Novelli is a professor in the McDonough School of Business at Georgetown University in Washington, D.C., and leads Georgetown's Global Social Enterprise Initiative. He also is co-chair of C-TAC, in Washington, D.C., and, from 2001 to 2009, served as CEO of AARP. Raca Banerjee is an associate at Heldman Simpson Partners in Washington, D.C. She served previously as policy and clinical models program manager for C-TAC.*

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# Understanding Cultural Gaps and Disparities in Advanced Illness Care

Interview by Marian Grant

A spiritual leader and a palliative care physician discuss the realities of culture and disparities in care for advanced illness.

**T**o achieve person-centered end-of-life care, we must address the cultural disparities in how each of us approaches this journey through a continual conversation that includes the person receiving care, family, caregivers, healthcare professionals, and spiritual advisors. On behalf of *Generations* journal, Marian Grant, director of Policy and Professional Engagement at the Coalition to Transform Advanced Care (C-TAC) in Washington, D.C., interviewed two people via phone who are intimately involved in advanced illness care, and who come from varied vantage points. Rev. Tyrone Pitts, D.Min., is the general secretary emeritus of the Progressive National Baptist Convention, chairman of the Board of the Morehouse School of Religion, and a senior advisor at C-TAC, Dr. Rebecca Aslakson is an associate professor of Anesthesiology and Critical Care Medicine at the Johns Hopkins Bloomberg School of Public Health in Baltimore, Maryland. She works as a physician in the surgical intensive care and palliative care units there, and is a palliative care researcher.

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**Generations:** You each have served in various roles regarding advanced illness and are both committed to helping the community to be more engaged in improving this type of care. What does it mean to “live well until the end” from a personal or community perspective?

**Rev. Pitts (TP):** As a person of faith, the phrase ‘to live well until the end’ captures the true meaning and significance of human existence. It recognizes the presence of God and spirituality in [the] human community. This phrase takes



Rev. Tyrone Pitts



Dr. Rebecca Aslakson

into account the importance of one’s transition from this life to the next. This journey of “to live

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**→ABSTRACT** Marian Grant, director of Policy and Professional Engagement at the Coalition to Transform Advanced Care (C-TAC), interviews both a spiritual leader and a palliative care physician about the cultural disparities in how we treat end-of-life care in America. Both parties agree that the wishes of the person who is at the end of their life must be put front and center, and that constant conversation between that person and their family, caregivers, physicians, and spiritual advisors is paramount to dispensing the best care possible. | **key words:** end-of-life care, health disparities, African American culture, advanced illness, communication

well until the end,” I believe, continues after my last human breath ends and once again transitions to its spiritual realm.

From a community perspective ‘to live well until the end’ calls upon health professionals, clinicians, hospitals, health plans, health systems, caregivers, and community and interfaith leaders to work together to promote a more loving and just society in which persons with advanced illness are afforded quality medical care that is comprehensive, person-centered, and honors their dignity, while at the same time fulfilling their emotional and spiritual needs. This approach to living well provides an opportunity for persons with advanced illness to peacefully transition from this life to the next, receiving the personal and spiritual support they need by respecting their wishes, their family’s wishes, and the wishes of their community.

This approach to the concept of living well compels clinicians, health professionals, health providers, and interfaith and community leaders to celebrate the person’s life by respecting their faith and beliefs in the power of the Holy Spirit to heal them, even if in [the health professionals’] opinion curing them is not possible. It also means that health professionals will use the best medical and technological advances at their disposal to alleviate the pain and suffering of persons with advanced illness, irrespective of cost. ‘Living well until the end’ challenges us all to make the life of persons with advanced illness meaningful and productive, providing them with the best care possible.

**Rebecca Aslakson (RA):** Living well is a personal decision; the expression is “if you’ve seen one death, you’ve seen one death,” because there is no common theme.

From a palliative-care perspective, my role is to understand each person’s goals and expecta-

tions, to also know the reality of what can be reasonably done medically, and then to match what medical resources are available with the person’s goals for their unique journey. If patients or families have unrealistic expectations, they need experienced clinicians to help steer them to a more practical plan. That is challenging when patients and families are asking for impossible treatments, or treatments that aren’t medically appropriate, and [such a challenge] calls for expert communication skills on the part of the clinician.

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***‘Living well until the end’ challenges us to make the lives of persons with advanced illness meaningful and productive, and to provide the best care.***

On a similar note, good medical care isn’t necessarily offering patients everything and then saying, ‘You pick.’ Good medical care is not assuming that the most aggressive treatments are the ones that individuals desire. Good medical care is also not fearing that you are somehow being a ‘bad’ clinician if you don’t offer ‘everything’ to every patient. Good medical care is exploring the medical goals of each person and family, as well as what role, as a medical provider, they want you to have as they move toward those goals.

We know that different people make different decisions in different ways, and need differing amounts of involvement and information from their clinicians. As a physician, I need to listen and communicate compassionately, respectfully, humbly, patiently, and clearly with every patient and family. Ideally, we discuss not only their unique medical goals and hopes, but also what we together identify as any upcoming medical decisions and what role they want for me [to take] in those decisions. Some families

want me to provide medical information and then they will essentially make any decisions on their own. Some patients and families want to discuss their goals, as well as the medical information, and then for us to make a decision together. Some patients and families honestly feel that medical decision-making is burdensome and they want me to make medical decisions for them.

Every patient and family is different . . . and you cannot respect those differences if you don't intensely and respectfully communicate to understand them. My responsibility is to work my hardest so that each patient and family can experience their medical care and make their medical decisions in the way that is right for them, their family structure, their spiritual and personal beliefs, and their unique culture.

**Generations:** What are the gaps or disparities in care received in the United States between communities or certain populations?

**TP:** Historically, there have been serious gaps in quality healthcare for many Americans due to race, class, gender, age, and sexual orientation. Unfortunately, African Americans and indigenous people in America have been the most underserved due to these historical gaps. These gaps have been exacerbated over the years due to politics and economics that have forced hospitals, health plans, and health services to use fee-for-service operational models that often run counter to the values of many of the physicians, health professionals, nurses, caregivers, and administrators that are called on to operate them.

Because of myriad financial and institutional demands, these operational health and hospital models often provide less and less medical and social support services to disadvantaged persons and their families who desperately need these services. What has evolved is an economically

driven, quality health system for the privileged few that provides outstanding services to those who can afford them and gives services of a much lesser quality to those who cannot. This has resulted in many persons from these underserved communities using the emergency room for primary care, and many often do not see a primary care physician at all.

Another gap in providing quality healthcare to underserved communities is the lack of trust and disrespect that has evolved over the years between the medical profession and racial and ethnic communities, due to miscommunication, misunderstanding, and misinformation about the cultures, traditions, and religious beliefs of racial and ethnic communities. This has resulted from medical experimentation and misuse of data by outside researchers who parachute into communities and engage in research through data collection, with little accountability to those communities. This often has led to serious mistrust and suspicion of almost all medical research, and any engagement in racial and ethnic communities from medical professionals that rely on data-driven approaches to decision making.

What is needed now more than ever is a new approach to building trust and reconciliation between African American and other communities that are disadvantaged by health disparities. Building bridges and developing relationships and mutual respect through the use of the South African concept of *Ubuntu*—'I am because we are, and we are because I am'—offers all of our communities the opportunity to close the gap of mistrust, as together we seek to build healthy communities of mutual respect and mutual trust.

**RA:** I would say that the biggest gaps are from lack of conversations. The system is geared toward providing all standard or possible treatments, which is not always in line with the

patient's goals. Some people make end-of-life plans, but most don't or haven't thought about it, and they may, by default, get aggressive medical treatments. . . . Without conversations about goals and options, patients are on track to get treatments they perhaps wouldn't have personally chosen. This crosses gender, ethnic, and age lines, but can be overcome with thoughtful and respectful planning and conversations. It also inherently involves listening—clinicians taking the time to listen to the patient's unique experiences, beliefs, and hopes. In such conversations, even populations who typically are reluctant to choose less aggressive treatments sometimes make less aggressive choices. And similarly, patients who want more aggressive treatments can be assured that they will receive those. The bottom line is honest, respectful, and compassionate bi-directional communication and trust-building.

Evidence supports [the idea] that communication gaps are more likely [to occur] between those of different racial, ethnic, or cultural backgrounds. Thus, even with appropriate training, providers, patients, and families from differing groups often are inherently likely to have less optimal communication.

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***You cannot respect patient and family differences without intensely and respectfully communicating to understand them.***

The solution isn't just to ensure that disadvantaged populations get the usual (aggressive) treatments, but rather that [there is] better communication so [they can receive] the right care. Some [individuals] from those populations are in an aggressive care treatment mode as a way to ensure they will get adequate care. This is a type of overcompensation; aggressive end-of-life care can be related to a lack of trust in the relation-

ship or communication. The solution then is to build better trust with patients and communities; to meet people where they are and vary treatment plans across individuals and communities; and to provide proactive communication.

An overall issue with advanced illness is uncertainty. Everyone—patients, families, and providers—has a different comfort level around uncertainty. As a clinician, you can't have an agenda or an idea of what you think is right for the patient—you have to be humble and open to their needs and goals.

**Generations:** What are some of the cultural differences in advanced illness care and how can community and religious organizations help bridge the gap between what the person wants and the care they receive?

**TP:** Many of the cultural differences [around] illness originate from the uniqueness of the cultures. To understand these various cultural approaches, one must be aware of the rituals, traditions, religious beliefs, customs, and mores of the cultures in question. Historically, in the African family in America, during and after slavery, caregivers primarily were family members and church members who provided for and supported each other. There were instances recorded during slavery that when slaves got old and couldn't work any

longer, the slave masters would free them and allow the older slaves to care for one another. It was the *community* that cared for the elderly, and those who suffered with advanced illness. Community members came together to support each other, and the African church in America became the community of support that gave meaning and hope to a community that was poor and oppressed.

With the institutions of racism in America, and with hospitals that were segregated or did not fully support the wishes of persons from my community, I suspect that things like advanced directives were not written down and given to physicians and institutions—due to the suspicion that if they were written down, then permission to do experimentation on their bodies would occur, and their final wishes would not be carried out. With the changing influences of American culture, many African American communities are not as cohesive as they were in the past. Consequently, the rituals, traditions, and culture embedded in the African religious experience in America that I experienced as a child are not as prevalent [now] as in the past. African Americans may refuse to write down advanced directives today because they are overly concerned that their wishes will be used in a way that is contrary to their desires, while others just don't want to deal with the reality of transitioning from this life to life eternal.

The challenge today is how health plans, hospitals, caregivers, and religious leaders can work together with existing community institutions to create a new paradigm of engagement that goes beyond conversation. This new paradigm would be one that seeks ways to engage with clinicians, advocates, and community and faith leaders to develop strategies of healing and wholeness that will provide opportunities to build bridges of mutual trust, mutual respect, and reconciliation with quality care.

**RA:** Religious and community organizations have lots of ways they can help—as facilitators, moderators, and advocates. There is already a role in end-of-life advocacy for spiritual leaders because these leaders already are often part of the end-of-life process and [attendant] rituals. We in healthcare could amplify their impact through more formal partnerships, training, and

systems to promote their involvement in advanced illness care. They often have a unique perspective: they know the patient and family and culture they are from.

However, I also think that spiritual leaders, like clinicians, should consider steering away from any potential agenda; clinicians and spiritual leaders benefit from being open to an individual person's goals, instead of just giving a medical or religious party line. I've sometimes seen spiritual leaders give antithetical information to patients when they are unaware of the true medical situation or treatment options. They may promise the person spiritual paths that directly advocate for unrealistic or unfeasible medical options. It isn't fair to patients [that they] hear one thing from their medical team, and then the opposite from a trusted spiritual leader. Thus, the way forward is [through] more and better partnerships between spiritual leaders and medical providers; both groups benefit by investing in deeper and more meaningful mutual connections that work toward a common goal of spiritually fulfilling and medically informed journeys for the people to whom they minister.

**Generations:** What is the role of family caregivers in advanced illness care?

**TP:** From an African American Christian perspective, the role of the family caregiver is essential to a person with advanced illness living life in its fullness. Central to the Christian faith is the mandate to love and care for one another. Almost all the United States' African American churches have some form of healthcare ministry and family caregiver ministry, both of which are actively engaged in the community. Consequently, family caregivers and health ministries are celebrated.

Within my African-Christian cultural experience, caring for another member of the

family is not only a responsibility, it also is a privilege and an opportunity to live one's life with meaning and purpose. Being a caregiver for a person who is facing the challenges of advanced illness almost always calls on the caregiver to become a consistent and determined advocate for that person. It sometimes requires that the caregiver advocate go beyond normal expectations of caregiving to ensure that the person with advanced illness gets the best care possible. They often give their all, sometimes becoming ill themselves, advocating for the best services possible for the people they love.

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***Within my African-Christian cultural experience, caring for another member of the family is not only a responsibility, it also is a privilege.***

As people of faith committed to the transformation of advanced illness care, we must seek ways to engage with communities of faith and caregivers to dismantle the roofs and glass ceilings of traditional health systems that prohibit persons from getting the best quality of care possible, by respecting their wishes and providing them with the support services needed to ensure that they live life in its fullness.

Doing so requires us to create a different approach to the fee-for-service system by supporting physicians, clinicians, health providers, nurses, and health workers who often are family caregivers, who often are overworked, and who do not receive the emotional and spiritual support they need. We must work with health systems, health plans, and health providers to do the impractical, perform the impossible, and create the unimag-

inable to ensure that the wishes of persons with advanced illness are respected, and that their spiritual, mental, and physical needs are met, and that their transition from this life to the next is celebrated. This offers us an opportunity to welcome the Holy Spirit to journey with us. It also offers us an opportunity as clinicians, healthcare workers, caregivers, and faith and community leaders to work together to create a better healthcare system.

**RA:** When patients get sick, their families get sick, and providers need to do right by both. Caregivers are a key part of the process. They can modify what patients feel and experience. They can be partners in caring for the patient. Conversely, if they have their own personal agenda, they also can obstruct the patient's goals. Just like patients, caregivers often have their own goals and values for that patient that need to be explored and understood. A big dose of humility for everyone is key.

One other point is that talking with both patients and caregivers about advanced illness and end of life can be difficult. Folks may need many small or big discussions, or compassionate nudges, before they decide to talk about advanced illness or end-of-life care wishes. Some people have a high [resistance to] change threshold and the topic is hard, physically and emotionally. So they may need to hear it in many different ways, in different contexts, to reach their [comfort] threshold. And there are always some holdouts who refuse to think or plan for this, despite the absolute necessity of doing so. As we say in palliative care, you need to “meet people where they are” and then work together to try to find the best way forward—for each individual person and family. 

# Building the Road Ahead: Reflections on the C-TAC National Summits

By Jon Broyles

Through a series of Summit events, C-TAC illuminated the road ahead toward improving and advocating for advanced illness care.

A story is told of a road being constructed through a thick forest. Many prospective workers apply to be on the crew. Just before the project commences, a man shows up and wants a job.

“Can you lay the tarmac?” the foreman asks.

“No.”

“Can you cut down the trees?”

“No.”

“Well, why are you here?”

“I can climb a tree—and that means I can see where the road should go,” says the man.

In the past four years, great progress has been made in improving advanced illness care for patients and families. The media is covering more stories on caregiving and end

of life; evidence-based care models (such as Sutter Health’s Advanced Illness Management [AIM], Home-Based Primary Care through the Medicare Demonstration, Independence at Home) have demonstrated greater patient satisfaction, higher quality, and lower costs than the status quo; and new bipartisan policy solutions are emerging.

This is the work of building the road. Every so often, though, we need to stop and ask: Are we on the right track? With this question in mind, the Coalition to Transform Advanced Care (C-TAC), convened a select group of leaders in the field—visionaries who could see the way ahead from their unique vantage

points—for a series of National Summits.

An alliance of 140 organizations, C-TAC believes that a number of core strategies need to be pursued simultaneously to transform advanced illness care: public engagement, professional education, development of clinical and community models, and policy advocacy. Working in and across these strategies, the Summit participants were our guides, helping to set the national agenda for change. The National Summits (literally, “high points”) that we held in 2013, 2015, and 2016 gave them a platform to convey their perspectives and call the country to action—or re-direction, as needed.

**→ABSTRACT** From 2012 to 2016, great progress was made in improving advanced illness care for patients and families: evidence-based care models demonstrated greater patient satisfaction, higher care quality, and lower costs; and new bipartisan policy solutions began emerging. To support this path forward, the Coalition to Transform Advanced Care wished to set a national agenda for change in advanced illness care by convening National Summits in 2013, 2015, and 2016. This article reflects on the lessons learned from those Summits—events that gave groups of experts in the field platforms to convey their perspectives and call the country to action and-or re-direction. | **key words:** *advanced illness care, C-TAC, C-TAC National Summits, end-of-life care*

On average, each Summit event drew 400 professionals from across the country, with a total of 120 speakers over the three years. Participants included, among others, policy makers, clergy, clinicians, consumer advocates, and financial planners. We have seen a variety of ideas and issues raised over the years, with the following common themes:

- Growing bipartisan support for policy change that supports advanced illness care;
- Partnerships and the power of the faith community;
- Creating a person-centered continuum of care across settings; and
- Technology and the development of common measures for the movement.

For 2017 and beyond, it is clear that a diverse set of stakeholders will need to continue to build a shared vision and agenda at the national, regional, and local levels. Lessons learned from our Summit series are included in this article, with the hope that stakeholders can start driving change in their own communities.

### **The 2013 Summit: Developing the Roadmap for Change**

“It’s our job to fix this,” said Jeff Thompson, M.D., then CEO of Gundersen Health System, summarizing the feeling in the room at our 2013

Summit. “The government can be our partners, but they can’t fix it for us. We need to make this the standard of care: care in line with patients’ wishes.”

The 2013 Summit established a common understanding between participants about the issues, challenges, and a shared sense of mission and action steps for achieving high-quality, advanced illness care. We found there were:

- **Powerful grassroots initiatives elevating the issue.** Local and state initiatives such as the Minnesota Honoring Choices initiative and the

eligibility rules, flexibility in benefit design, and pilot-testing through the Centers for Medicare & Medicaid (CMS). As a result of growing bipartisan consensus, CMS would later propose and authorize payment to physicians for voluntary advance care planning discussions with patients.

- **Person-centered care models that work.** Case studies from Sutter Health, Allina, Gundersen Health System, and others were widely discussed. “We need a system of care that can honor

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## ***A number of core strategies need to be pursued simultaneously to transform advanced illness care.***

Conversation Projection were starting to gain traction. In addition, The Institute of Medicine (now the National Academy of Medicine [NAM]) announced their plans to issue a second report on dying in America, nearly ten years after their first (IOM, 2014).

- **Emerging bipartisan policy solutions.** Incremental policy options were slowly emerging following political gridlock. Sens. Johnny Isakson (R-GA) and Mark Warner (D-VA) had recently introduced the bipartisan Care Planning Act. Other policy options examined the alignment of value-based incentives with quality measures, changes in hospice-

patient choices—this is what all of these models are trying to do, [to] provide a real choice,” said Diane Meier, M.D., director of the Center to Advance Palliative Care.

These models both increase care quality and lower costs through better care coordination to reduce repeated and unwanted tests, effective home and community supports, and improved communication with the care team and exploration of care options.

### **The 2015 Summit: Driving Change Through Leadership, Evidence, and Action**

“In the midst of this illness, hope and dignity keep me on the battlefield,” said Rev. Diane

Smalley at the keynote address during C-TAC's 2015 Summit.

When she gave the keynote, Rev. Smalley had been living with advanced-stage cancer for many years. She pointed to the care model that she relied upon, what she called her “dream team”: her primary care clinicians, working in partnership with her oncologist and faith community to meet her physical and spiritual needs and allow her to stay active in her community as an advocate. In Rev. Smalley's words, we need more dream teams—multi-disciplinary, multi-sector, community-based partnerships focused on the needs of people with serious illness. Victor Dzau, M.D., the president of the National Academy of Medicine, also championed this model team concept, saying, “I see a future full of partnerships.”

The 2015 Summit discussion centered on the following areas:

- **Supporting the development of a new workforce.**

Drawing on the 2014 *Dying in America* report (IOM, 2014), Jean Kutner, M.D., reminded us that “all clinicians should be competent in basic palliative care, including communications, interprofessional collaboration, and symptom management. Schedulers through to clinicians are needed—we can only do this as a team working at the top of our skillset.”

Speakers pointed to the Advancing the Palliative Care

and Hospice Education and Training Act legislation, which was building strong bipartisan support, to encourage more training for palliative care providers.

Family caregivers too, are critical—yet often unacknowledged—members of the care team, as Senior Vice President and Director of AARP Public Policy Institute Susan Reinhard, R.N., demonstrated through the *Home Alone* report research (Reinhard, Levine, and Samis, 2012).

Advocacy efforts at both the state (e.g., the Caregiver Advise, Record, Enable Act) and national levels (e.g., Recognize, Assist, Include, Support and Engage Act) on supporting family caregivers were gaining traction.

- **Fostering trust and alignment among major community leaders/partners.** The faith community through the Alameda County Care Alliance, a collaboration of five churches, Kaiser Permanente, C-TAC, and University of California, Davis, emerged as a powerful catalyst in increasing access to palliative care, social supports, and care planning through their trusted relationships.

Speakers also highlighted partnerships that could work with value-based payment models (e.g., Accountable

Care Organizations) across care delivery models to create a person-centered continuum of care, such as home-based primary care,

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***‘We need to make this the standard of care: care in line with patients’ wishes.’***

advanced illness management, and hospice. Cheryl Phillips, M.D., senior vice president for Public Policy and Health Services at LeadingAge, pointed to a number of effective models in cities (San Francisco) and states (Vermont) where health systems had forged collaboratives with community anchors such as affordable housing organizations and senior centers.

What all of these partnerships have in common is that they put the patient at the center. Bud Hammes, director of Respecting Choices, an evidence-based systematic approach to advance care planning developed at Gundersen Health System, found that the best place to start activating person-centered care is to help people connect their deep personal and family goals with their medical care.

- **Aligning public policy with public attitudes.** In January 2015, just before the Summit, Medicare—for the first time in the program's history—set clear goals for moving

providers away from fee-for-service payments to value-based or alternative payment models. This direction of health reform lays important groundwork in redesigning care for individuals with advanced illness by allowing payers and providers greater flexibility in building models that work best for their population.

### The 2016 Summit: Building Bridges to Success

“It’s rare when any generation has the ability to impact their field in the way you have today—to build a system of care that’s more equitable and person-centered,” said Rick Pollack, president and CEO of the American Hospital Association, at the 2016 Summit.

Summit participants focused on the new frontier: achieving scale, implementing creative solutions (including technology), and measuring progress. As Joseph Milano, M.D., medical director at Northwell Health’s Housecalls program said, “We’re now hitting the middle phase [and] we now need to think about sustainability . . .”

The 2016 Summit discussion centered on the following areas:

- **Measuring the movement.** To create a sustained scaling of effective interventions, Summit participants agreed that a national, coordinated framework for delivering and measuring effective, person-

centered advanced illness care was needed. Arif Kamal, M.D., noted, “There are no measures for coping and rapport-building. There is a misalignment between where we think we should focus and where quality measures actually are.”

Despite these challenges, participants agreed that measures were critical and they felt encouraged by efforts underway at the National Quality Forum, The Pew Charitable Trusts, and the Gordon and Betty Moore Foundation (among others) to identify patient-centered measures across clinical and community settings.

- **Harnessing advances in technology.** Former U.S. Senator Tom Daschle spoke of the power of technology and policy as a broad trend. “Technology has exploded and we’re seeing all kinds of new applications. I don’t think policy has kept pace with the technological innovation we’ve seen, and so

medicine at Brigham & Women’s Hospital, said, “Even with the perfect financial incentives and clinician willingness, we still need help identifying who among our patients needs counseling.” New technology tools are now available to help, such as online care planning that is tied to electronic health records to ensure that a person’s wishes are known and accessible at the point of care and are easily identifiable by providers.

### Conclusion

We know that an estimated 10,000 baby boomers are turning age 65 every day and that by 2030, 9 million Americans will be older than age 85, and many will experience substantial disability and chronic conditions associated with older age. Undoubtedly, with the growing number of older Americans who will need high-quality, person-centered care, there is an urgency to advance our collective work.

The cache of findings

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***‘Even with the perfect financial incentives and clinician willingness, we still need help identifying who among our patients needs counseling.’***

it will be incumbent upon the next Administration and the next Congress to see if we can continue to move policy to keep up.”

Ziad Obermeyer, M.D., assistant professor of emergency

shared above illustrate that the enormous task before us is made more feasible, grounded as it is in a shared personal experience with advanced illness, beyond political or professional labels. Emphasizing

this point during the 2016 Summit, Congressman Phil Roe (R-TN) said, “What you see up here are four politicians, two Republicans, and two Democrats; but we are four people—four people who are going to go through this with their family. You’re going to be born on this earth and you’re going to die, and your having a say in how you do that, I think, [is] very, very important.”

As Congressman Roe’s comment indicates, facing advanced illness is a difficult, intensely personal journey. Starting by considering our own stories ensures that we are open to recognizing common-

alities and empathizing with others. No matter our trade, religion, or political leaning, we can recognize that values like hope, determination, and community can counteract fear, distraction, and isolation; personal stories and shared experiences form the essential basis of many meaningful collaborations, ideas, and policy proposals put forward by Summit participants.

And as we collectively move forward, we must return to reflections like Congressman Roe’s, Rev. Diane Smalley’s, and our own stories and ask—as we would of the person in the tree with a clear view—are we on

the right track? Are we making progress? What do you see ahead? 

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Jon Broyles is executive director of the Coalition to Transform Advanced Care, in Washington, D.C.

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COMING UP IN  
**Summer  
2017**

### **From the Summer of Love to 2017: Baby Boomers Come of Age**

W. Andrew Achenbaum, Erlene Rosowsky, and Mercedes Bern-Klug, **Guest Editors**

The Summer of Love in 1967 stands as a seminal moment in U.S. history, when the counter-culture entered the mainstream and the rest of America saw firsthand the power of anti-war activism, free love, feminism, and drug- and music-fueled optimism. The Summer 2017 issue of *Generations* will explore how this culture shift influenced the baby boomers, and how this cohort is now experiencing later life. How is this group, which broke traditions in the 1960s, faring now as they are long past the age they said was not to be trusted? The issue will address generational dichotomies, women’s roles, global violence and the impact of military conflicts, love in older age, retirement, pressures to remain “young,” friendship, caregiving, and general post-1968 expectations, illusions, and disillusion.

# Generations

# Supporting the Patient Voice: Building the Foundation of Shared Decision-Making

By Patricia Bomba

Early engagement is important in shared decision-making about care: some programs have successfully improved documentation and clinical application of these care decisions.

Throughout their lives, patients are frequently faced with making complex medical decisions requiring them to choose between many options, to face uncertain outcomes, and to weigh the potential benefits and harms of treatment—all decision-making components that are valued differently by each individual. But at no time is shared decision-making more important than near the end of life.

***It is important to move the shared decision-making process on care choices upstream and use it consistently over the life course.***

Shared decision-making is neither clearly nor consistently defined in the research literature (Institute of Medicine [IOM], 2014). However, the essence of shared decision-making moves medical decision-making from the extremes of paternalistic, physician-centered

beneficent decisions and patient-autonomous decisions to a person-centered model in which the physician and patient share the process.

For persons who are seriously ill and might die within a year, making life-and-death decisions to withhold and-or withdraw life-sustaining treatment requires thoughtful discussions and shared medical decision-making that is done within scope of practice. To best employ a shared approach for making complex medical decisions, it is important to move the process upstream and use it consistently throughout the course of a patient's life.

## **Moving Shared Decision-Making Upstream**

The national Choosing Wisely campaign demonstrates one attempt to move shared decision-making upstream. The American Board of Internal Medicine (ABIM) Foundation in 2012 rolled out Choosing Wisely to promote conversations between physicians and patients that would help avoid unnecessary testing and medical

**→ABSTRACT** Shared decision-making is critical to a model of care that places the person at the center of treatment decisions, from birth to death. To ensure an individual's treatment preferences are honored at the end of life, shared decision-making must be person-centered and well-informed. Physicians and other clinicians must be trained, comfortable with necessary discussions, and act within their scope of practice. Similarly, the patient and-or other medical decision-maker must be prepared to actively participate in the process. A multidimensional community approach to advance care planning is essential. | **key words:** *end-of-life care, shared decision-making, advance care planning, POLST, eMOLST, MOLST*

expenses (Wolfson et al., 2014). Some estimates suggest that as much as 30 percent of all health-care spending is wasted (Berwick, 2012).

While the initial focus of *Choosing Wisely* was on overuse of medical resources, the campaign also emphasizes treatments that place patients at risk for harm, and aims to help make sure patients get safe, high-quality care (Cassel and Guest, 2012). Patients are encouraged to consult with their physicians and, through shared decision-making, “choose care that is supported by evidence, not duplicative of other tests or procedures already received, free from harm, and truly necessary” (ABIM Foundation, 2016).

The principles of shared decision-making are well-documented. While there is some guidance about how to approach shared decision-making in routine clinical practice, it is not well-integrated into current clinical practice (Elwyn et al., 2012). From personal clinical experience, a practical approach is to consistently apply a simple framework for shared decision-making, integrating the person’s health status and prognosis, and asking the following questions:

- Will the treatment make a difference?
- What are the benefits and burdens? Or, how might the treatment help and how might it be harmful?
- Is there hope for recovery? If so, what will life be like afterward?
- What does the person value? What matters most and makes life worth living? What are the person’s goals for their medical care?

These key questions can also apply to making decisions about wellness activities, medications, non-pharmacologic interventions, blood work, diagnostic and imaging studies, and life-sustaining treatment. Simply frame the questions around the area of decision making; e.g., ask “Will quitting smoking make a difference?” and follow up with the additional questions, as listed above.

If clinicians can integrate the shared decision-making process as part of their routine practice, this will enhance their ability to use the

model for persons with advanced illness who might die within a year. Arriving at final decisions may require a series of thoughtful discussions, which can be supported by decision aids, such as the “Benefits and Burdens of Tube Feeding/PEG Placement” (Monroe County Medical Society, 2014).

### **Making Decisions About Life-Sustaining Treatment**

Shared medical decision-making for patients with advanced illness is a key component of person-centered, family-oriented healthcare—care that combines chronic disease management with the key pillars of palliative care, including advance care planning, pain and symptom management, and caregiver support integrated with psychosocial, religious, and spiritual care. It is a process in which physicians, at times in collaboration with other clinicians (such as nurse practitioners), and patients work together to make decisions. Early steps in this process include ensuring the patient has the capacity to make the decision, and clearly understands his or her current health status and prognosis.

The shared decision-making process is especially important toward the end of life, when one’s ability to make medical decisions may diminish for a short period of time due to acute illness, delirium, etc., or permanently, because of dementia. Due to the sensitivity of the decisions to be made and the risk of incapacity, the process must also be family-oriented: family members, loved ones, and the person’s designated medical decision-maker must know his or her values, beliefs, goals for care, and preferences for treatment.

Tests, treatments, and care plans are selected based on clinical evidence that balances benefits, risks, and expected specific treatment outcomes in light of the patient’s current health status and prognosis, and take into consideration his or her values, beliefs, and care goals.

It is important to recognize that making complex medical decisions is difficult for indi-

viduals, even for those with medical training, and especially for patients who are near the end of life.

Thus, the physician may offer an opinion to help with decision making when it is medically complex, as long as it aligns with the person's goals for care. Physicians are not obliged to offer treatments that will not work; for example, physicians should not offer trials of Bilevel Positive Airway Pressure to a person with end-stage dementia.

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***'Physicians are not obliged to offer treatments that will not work.'***

Furthermore, physicians must honestly and compassionately share medical evidence that affirms a treatment is unlikely to work and-or will cause more harm than good. For example, there is consensus about the recommendation to avoid use of feeding tubes in persons with advanced dementia (Fischberg et al., 2013). Additionally, cardiopulmonary resuscitation (CPR) is intended to prevent sudden, unexpected death. CPR is not indicated in cases of terminal, irreversible illness where death is expected, or in medical situations where CPR is deemed ineffective. Survival rates after a cardiac arrest are poor (less than 1 percent) in persons with advanced illness, such as end-stage heart failure or metastatic cancer, due to the underlying disease and not the failure of the intervention. Even if the patient survives, there is likely to be significant impairment.

Difficulty in decision making arises when recovery cannot be predicted. In this case, a short-term trial of life-sustaining treatment may be desired. These trials must begin with clarifying the patient's goals for care and require active discussions between the physician and the patient about the most appropriate course of treatment. Goals for care often evolve from a focus on longevity, to functionality, to comfort care.

Consider a woman with end-stage chronic obstructive lung disease with multiple admis-

sions for respiratory failure requiring intubation and mechanical ventilation. During her last admission, she had difficulty being weaned off the ventilator. She does not want to be dependent on a ventilator to live, but hopes to see the birth of her first grandchild, anticipated in three months. The woman expressed her preference for another trial of intubation and mechanical ventilation should she experience acute respiratory distress due to a bout of pneumonia or congestive heart failure. If a trial is not effective, she would not want a tracheostomy. Her goals for care should be discussed again after the birth of her grandchild, and to clarify how her treatment preferences may or may not change.

If the treatment is no longer beneficial, it is legally and ethically appropriate to discontinue such treatment, recognizing it is the underlying disease, not the act of withdrawing treatment, which causes death. There is no medical, legal, or ethical distinction between withholding and withdrawing life-sustaining treatment. If such a distinction existed in the clinical setting, a patient might refuse treatment that could be beneficial, out of fear that once started, it could not be stopped.

**Shared Decision-Making When the Person Lacks Capacity**

Each individual has the right to make his or her own medical decisions (U.S. Congress, 1990). If the individual is unable to make medical decisions, the designated medical decision-maker must make healthcare decisions in accordance with the person's wishes, including the person's religious and moral beliefs. Designated medical decision-makers are called health care agents, proxies, power of attorney for health care, or surrogates in different state-specific advance directive documents (National Hospice and Palliative Care Organization, 2016). In this article, the term "health care agent" is used to indicate an individual designated in an advance directive, which is called a "health care proxy." A "surrogate" is a person who, by default, becomes

the decision maker for an individual who has no appointed health care agent.

The primary purpose of creating a legal document like a health care proxy is to extend patient autonomy beyond the loss of decision-making capacity. Health care agents are appointed to advance the wishes and values of the patient, not to disregard them and substitute their own wishes and values when participating in shared decision-making (Bomba and Karmel, 2015).

Different states have different laws governing end-of-life decision-making (National POLST Paradigm Task Force, 2014). For the purpose of this article, the legal requirements that embody the ethical framework for making decisions regarding life-sustaining treatment under New York State Public Health Law (NYSPHL) will be used for illustrative purposes.

As per NYSPHL, a person is presumed to have the capacity to make his or her own decisions, unless a physician assesses the person and determines that he or she is unable to make a specific medical decision; this determination must be confirmed by a second physician (Bomba and Karmel, 2015). Variation in state public health law may define who can determine capacity. Without regard to the variations, the clinician should be trained and qualified, as clinicians must be able to assess a patient's capacity early in the process of shared decision-making. Capacity training is an integral component of New York's clinician training on advance care planning.

Capacity is the ability to take in information, understand its meaning, and make an informed decision using that information. Intact capacity permits functional independence. Capacity requires a cluster of mental skills people use in everyday life and includes memory, logic, the ability to calculate, and the innate flexibility to turn attention from one task to another.

Medical determination of capacity often is difficult; and there is no standard tool with which to do this. Capacity assessment is a com-

plex process and is not simply determined by the Mini-Mental Status Exam. Assessments should involve a detailed history from the patient and collateral history from family; a focused physical examination, including cognitive, function, and mood screens; and appropriate testing to exclude reversible conditions that may affect the ability to make decisions.

Capacity requirements vary by task. The capacity to choose a trusted individual as an appropriate health care agent differs from the capacity to agree to a medical procedure or treatment. The ability to make medical decisions may vary based upon treatment complexity. An individual may be able to make simple healthcare decisions or request palliation and relief of pain and suffering, but may be unable to make complex decisions regarding cardiopulmonary resuscitation and life-sustaining treatment.

Because the health care agent will make medical decisions if the person loses his or her capacity to make such decisions, the health care agent should be part of the discussion and must abide by the person's decisions. Additionally, if the individual loses the ability to make complex decisions with worsening health status and prognosis, prompting a change in the goals for care, medical decisions to forego specific life-sustaining treatment documented as medical orders must be followed and cannot be changed by a designated health care agent. However, the health care agent can make additional treatment decisions to withhold and-or withdraw life-sustaining treatment consistent with the person's values, beliefs, and goals for care.

### **Advance Care Planning as a Wellness Initiative**

Advance care planning is a process of planning for future medical care in the event that an individual is unable to make his or her own medical decisions. Advance care planning assists an individual in preparing for a sudden unexpected illness or injury (from which an individual may recover), as well as the dying process and,

ultimately, death. The introduction of advance care planning as a communication process when a person is healthy and well and-or earlier in the patient's disease course can also improve shared decision-making, specifically by framing advance care planning as a wellness initiative.

The advance-care-planning process should result in a legal document called an advance directive. There are two types of advance directives: the health care proxy (also known as the durable power of attorney for health care) and the living will. The critical document is the health care proxy. The key issues to consider include choosing the right health care agent, clarifying values, beliefs, and goals for care, and having a meaningful conversation with the agent, family, loved ones, and caregivers, as well as with primary and specialty physicians involved in the person's care. These issues are

consistent with a key recommendation for public education and engagement found in the IOM report, *Dying in America* (IOM, 2014).

Initiating advance care planning is relevant at all ages, as no one is immune from acute illness, injury, complex chronic conditions, or death. For all adults, advance care planning should begin at age 18. Improving communication and advance care planning is critically important for individuals of all ages, including adults, adolescents, and children. While children younger than age 18 cannot complete a health care proxy, seriously ill children may have the capacity to participate in shared decision-making and should have the opportunity to do so (NQF, 2006; IOM, 2014). From a population health perspective, encouraging advance-care-planning discussions should be integrated into key life milestones; for example, when applying

**Table 1. What to Keep in Mind When Choosing a Health Care Agent**

Meet legal criteria (be a competent adult, at least 18 years old)
Be willing to speak on behalf of the person
Be willing to act on the person's wishes
Be able to separate his/her own feelings from those of the person
Live near the person or be willing to come to that geographical location, if needed
Know the person well
Understand what values, goals, and morals are important to the person
Be willing to discuss sensitive wishes
Be willing to listen to wishes expressed by the person
Be willing and able to work with those providing care to the person to carry out those wishes
Intend to be reasonably available in the future
Be able to handle potential conflicts between the family and close friends of the person
Be willing and able to handle the responsibility of carrying out end-of-life wishes
If chosen as an alternate, be willing and able to act if the primary HCA is unwilling or unable to act

Source: Community Conversations on Compassionate Care Advance Care Planning booklet. Copyright, Excellus BlueCross BlueShield, used with permission.

for a driver’s or marriage license, or matriculating to college, etc. (IOM, 2014).

**Community Conversations on Compassionate Care program**

The Community Conversations on Compassionate Care (CCCC) ([goo.gl/4BFDOJ](http://goo.gl/4BFDOJ)) program launched in 2002 to encourage early advance-care-planning discussions and the completion of advance directives, particularly healthcare proxies, and has yielded positive outcomes (Bomba and Orem, 2015). CCCC combines storytelling and behavioral readiness theory outlined in “Five Easy Steps” for completing the process. The program focuses on choosing the right health care agent, as outlined in Table 1 (see page 25), and sharing personal values, beliefs, and goals for care. The CCCC program encourages individuals to learn to make medical decisions upstream by employing a shared decision-making model that uses the four key questions noted at the beginning of this article.

**National POLST Paradigm**

While advance directives are key legal documents, medical personnel cannot interpret and follow them in an emergency, as they may not

apply in the current clinical situation. However, emergency medical personnel can follow medical orders. Persons with advanced illness who might die in the next year and-or are of advanced age may also work with their physician to complete the process that results in a Physician Orders for Life-Sustaining Treatment (POLST) Paradigm form.

Completing a POLST form is a clinical process designed to facilitate discussion between the physician and the patient and his or her family, loved ones, and caregivers; other members of the care team can participate in the process within scope of practice. A POLST form creates a set of actionable medical orders that all healthcare providers, including EMS personnel, must follow in all settings. A key feature of POLST is that it is based on the patient’s current health status, prognosis, and goals. This is a critical difference between an advance directive and a POLST. Since a POLST is completed for current treatment, the burden of making these decisions is lifted off of family members. (See Table 2, below, for a detailed chart that shows the differences between Advance Directives and POLST [Bomba, Kemp, and Black, 2012]).

**Table 2. Differences Between POLST and Advance Directives**

Characteristics	POLST	Advance Directives
Population	For the seriously ill	All adults
Timeframe	Current care	Future care
Who completes the form	Healthcare professionals	Patients
Resulting form	Medical Orders (POLST)	Advance directive
Health care agent or surrogate role	Can engage in discussion if patient lacks capacity	Cannot complete
Portability	Provider responsibility	Patient/family responsibility
Periodic review	Provider responsibility	Patient/family responsibility

Source: Reprinted with permission from: Bomba, P. A., Kemp, M., and Black, J. S. “POLST: An Improvement Over Traditional Advance Directives.” *Cleveland Clinic Journal of Medicine* 2012; 79: 457–464. Copyright © 2012 Cleveland Clinic Foundation. All rights reserved.

**Table 3. The 8-Step MOLST\* Protocol****1. Prepare for discussion:**

- Review what is known about patient and family goals and values
- Understand the medical facts about the patient's medical condition and prognosis
- Review what is known about the patient's capacity to consent
- Retrieve and review completed Advance Directives and prior DNR documents
- Determine who key family members are and, if the patient does not have the capacity, see if there is an identified health care agent, guardian, or healthcare representative
- Find uninterrupted time for the discussion

**2. Begin with what the patient and family know:**

- Determine what the patient and family know regarding condition and prognosis
- Determine what is known about the patient's views and values in light of the medical condition

**3. Provide any new information about the patient's medical condition and values from the medical team's perspective:**

- Provide information in small amounts, giving time for response
- Seek a common understanding; understand areas of agreement and disagreement
- Make recommendations based on clinical experience and in light of the patient's condition

**4. Try to reconcile differences in terms of prognosis, goals, hopes, and expectations:**

- Negotiate and try to reconcile differences; seek common ground; be creative
- Use conflict resolution when necessary

**5. Respond empathetically:**

- Acknowledge
- Legitimize
- Explore (rather than prematurely reassuring)
- Empathize
- Reinforce commitment and non-abandonment

**6. Use MOLST to guide choices and finalize patient and-or family wishes:**

- Review the key elements with the patient and-or family
- Apply shared medical decision-making
- Manage conflict resolution

**7. Complete and sign MOLST:**

- Get verbal or written consent from the patient or health care agent, guardian, healthcare representative
- Get written order from the treating physician and witnesses
- Document conversation

**8. Review and revise periodically**

\*MOLST is a medical order form designed to provide a single, community-wide document that would be easily recognizable and enable patient wishes for life-sustaining treatment to be honored. This 8-Step Protocol was originally developed by Dr. Patricia Bomba for the MOLST Program of New York State. Program information is found at [www.CompassionandSupport.org](http://www.CompassionandSupport.org). Copyright, Patricia Bomba, M.D., M.A.C.P., Excellus BlueCross BlueShield, used with permission.

The IOM report, *Dying in America*, recommends implementing policies and payment systems to support high-quality end-of-life care, including “encouraging states to develop and implement a Physician Orders for Life-Sustaining Treatment (POLST) paradigm program in accordance with nationally standardized core requirements” (IOM, 2014). State programs are in various stages of development; the latest information is accessible on POLST.org. POLST forms are state-specific and vary based on individual state needs and regulations. State programs vary in name (e.g., Medical Orders for Life-Sustaining Treatment [MOLST]; Clinician Orders for Life-Sustaining Treatment [COLST]; Medical Orders for Scope of Treatment [MOST]; Physician Orders for Scope of Treatment [POST and POLST]), as well as in how they are de-

signed, managed, and executed (National POLST Paradigm Task Force, 2014).

**Ensuring Accessibility to Properly Completed POLST Forms**

New York is a founding state of the National POLST Paradigm Task Force. The program in New York, called MOLST, meets the nationally standardized core requirements for POLST Paradigm programs. Development began as a community initiative in 2001 to address consumer concerns that advance directives were not being followed.

**MOLST focuses on quality of the process**

In accordance with the National POLST Paradigm, New York’s MOLST focuses on the quality of the conversation, documentation of the

**Table 4. A Multidimensional Approach to Effective NY MOLST & eMOLST Implementation**

Culture change*
Professional training of physicians, clinicians, and other professionals*
Public advance-care-planning education, engagement, and empowerment*
Thoughtful discussions*
Shared, informed medical decision-making*
Care planning that supports MOLST
System implementation, policies and procedures, workflow
Dedicated system and physician champion in all community settings
Leverage existing payment stream (CPT codes 99497 and 99498) to encourage upstream shared, informed, decision-making*
Standardized interoperable online completion and retrieval system available in all care settings to ensure accuracy and accessibility (e.g., NYSeMOLSTregistry.com)*
In the future: sustainable payment stream based on improved compliance with person-centered goals, and preferences for care and treatment, measured by: <ul style="list-style-type: none"> <li>▪ improved resident/family satisfaction</li> <li>▪ reduced unwanted hospitalizations</li> </ul>

\*These recommendations were affirmed and/or recommended in the 2014 IOM report, *Dying in America*. Copyright, Patricia Bomba, M.D., M.A.C.P., Excellus BlueCross BlueShield, used with permission.

clinical process, and following the ethical and legal framework for making end-of-life decisions to ensure access to a properly completed MOLST form. The need for a standardized clinical process was recognized with early implementation efforts. The 8-Step MOLST Protocol outlined in Table 3 (see page 27) was introduced in 2005 and revised in 2011 to comply with significant changes in NYSPHL (Bomba, 2011). It is easily adapted for any state's POLST Paradigm program. Seven legal requirements checklists in New York support the clinical process to ensure the shared decision-making process is completed correctly (New York State Department of Health, 2013).

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***Medical personnel cannot interpret and follow advance directives in an emergency, as they may not apply to the current clinical situation.***

Early on, New York envisioned creating a registry and an electronic version of the MOLST form and process. New York's eMOLST system, accessible at NYSeMOLSTregistry.com, incorporates MOLST form completion, MOLST process documentation, and also serves as a registry of MOLST forms for New York State. The online MOLST completion system provides a standardized clinical process, the ethical and legal framework to document personal values, beliefs, and goals for care that in turn drive the choice of the life-sustaining treatments individuals wish to receive and/or avoid at that point in time. The eMOLST system also includes embedded educational links and videos that physicians and other clinicians can use as part of the discussion. Quality assurance is built in with logic-based coding to ensure an eMOLST form created in NYSeMOLSTregistry.com is completed with 100 percent accuracy.

The eMOLST system allows clinicians to print forms to integrate with paper records, or the Web-based application can be electronically

integrated with an electronic medical record. The eMOLST system provides access twenty-four hours a day, seven days a week to eMOLST forms for any provider with access to the registry. The program is designed to improve clinical outcomes, legal outcomes, provider satisfaction, and meet the needs of health systems seeking to reduce patient harm and achieve the Triple Aim.

With fifteen years of consistent leadership, New York has addressed challenges and shared best practices and lessons learned with other states and national leaders. Effective implementation of MOLST and eMOLST requires a multi-dimensional approach as outlined in Table 4 (see page 28).

### **Conclusion**

The key recommendations in the IOM report, *Dying in America*, support a care model for shared decision-making that begins with early advance-care-planning discussions and completion of healthcare proxies (IOM, 2014). Use of a shared decision-making model over the course of a person's lifetime will engage and empower the individual and prepare him or her and his or her family for end-of-life decision-making focused on "what matters most." A multi-dimensional approach is needed to ensure accessibility to properly completed and documented POLST Paradigm forms. New York's approach includes implementation of eMOLST supported by physician or clinician training and public education to ensure well-informed, effective shared decision-making. 

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# Advance Care Planning: Ensuring Patients' Preferences Govern the Care They Receive

By Brad Stuart,  
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Benjamin W. Moulton

Advance directives, POLST forms, and physician discussions are crucial for patient care, as are the programs working to implement them.

As the United States population ages and chronic illness prevalence grows, advance care planning has become the most effective tool individuals can employ to make sure they receive the care they want—care that aligns with their values and preferences. Such planning can help prevent painful and potentially ineffective interventions that are based on clinical urgency alone, such as the series of revolving-door hospitalizations that patients may undergo near the end of life.

Advance care planning is a comprehensive process involving communication among patients, caregivers, and their clinicians. Done well, it results in a personalized and flexible plan of care that can grow and change as illness advances. Ideally, this planning evolves over time. It is more than a one-shot conversation around the dinner table or at the doctor's office, although those conversations are vital preliminary steps.

Advance directives are one product of the care-planning process. They serve as tools to

communicate patient preferences to clinicians, who can then provide the care patients want. Although advance directives have been in use since the early 1990s, they are not yet standard in clinical practice for several reasons. Many patients are not familiar with them, clinicians may not routinely review patients' advance directives with them even when they are in the medical record, and they are underused in cases of serious illness, where they are most needed. Even when available at the point of care, advance directives do not always ensure that care aligns with patient preferences.

The 2014 Institute of Medicine (IOM) report, *Dying in America*, suggests some of the reasons advance directives have failed to meet expectations: an inordinate amount of energy is directed toward completing the documents, instead of toward conversations about patient values to determine the preferences that form the core of advance directives; most clinicians lack training in how to hold these patient-centered conversa-

**→ABSTRACT** Advance care planning often determines whether patients will undergo only tests and procedures they want, and pursue their goals, or receive clinically driven treatment. In advance care planning, patients and clinicians work to achieve fully informed consent through shared decision-making. Patient preferences are documented and made available to clinicians who may need them. POLST forms, supplemented by advance directives designating a surrogate decision-maker, may be the best way to make patient preferences accessible and drive care decisions. New care delivery models such as Independence at Home and Advanced Illness Management are needed to make advance care planning routine. | **key words:** *advance care planning, shared decision-making, POLST, Independence at Home, Advanced Illness Management*

tions; even when completed, such forms often are too vague to direct care; during clinical crises, advance directives often are unavailable to the clinicians who need to make rapid decisions about interventions; and familial uncertainty and-or disagreement can create significant barriers (IOM, 2014).

## Two Vital Components of Advance Care Planning

For advance care planning to be successful, clinicians and patients need to collaborate to achieve two important objectives: fully informed consent and shared decision-making.

**Fully informed consent** means that patients and their loved ones understand the risks, benefits, and alternatives to the proposed treatment, and accept the facts about the nature of their illness, the ways their disease is likely to progress, their prognosis, and their options for care. The goals of care may range from the most invasive hospital treatments to care focused mainly on comfort, pain and symptom control, and emotional and spiritual support. Once patients (or their surrogate decision-makers, if the patient is too ill or confused to participate) more fully comprehend these details, they are more prepared to make informed choices about their goals of care. They are better equipped to consent to the goals they actually want, or to refuse invasive procedures they may want to avoid.

More than just a next step, **shared decision-making** is really the core of informed consent, a much more comprehensive give-and-take than the standard ritualistic information provided by the doctor prior to the patient signing a form. Shared decision-making is the bi-directional exchange of information between patients and their clinicians about risks, benefits, and alternatives. Clinicians may voice what options they think are best for the patient, then the patient can check these recommendations against their own choices. The outcome of this process is a list

of the patient's formal preferences for care. These preferences are recorded by the clinician and, if possible, entered in an electronic medical record so all other clinicians who might encounter the patient in any setting, including the emergency room or the hospital, have access to these preferences for care. Shared decision-making helps patients factor clinicians' opinions into their preferences, and also helps to ensure clinicians and patients are literally on the same page regarding the patient's goals of care.

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## *Advance directives communicate patients' preferences to clinicians, who can then provide the care patients want.*

With fully informed consent and shared decision-making, the preferences that emerge from this process are much more powerful than simple advance directives. Both patient and clinician know what one another is thinking, and the clinician is aware of the patient's wishes. Imagine being a doctor in the emergency room reading an advance directive that was written years ago. Who knows if that document still represents what the patient wants? Values and wishes change over time as people gain experience with illness. Preferences arrived at through fully informed consent and shared decision-making (assuming they are kept current as patients and clinicians stay in communication over time) are likely to help patients get the care they actually want.

## Barriers to Advance Care Planning

Although advance directive documents and state legislation supporting them have been implemented over the past three decades in most states, reform of medical school curricula and postgraduate residency training about advance directives have progressed much more slowly. Palliative care and hospice education for clinicians, including training in communications and advance-care-planning conversations, is under-

emphasized in medical undergraduate education. Furthermore, there is no gold standard for teaching students to conduct these conversations, and there is still no certainty that current medical training improves healthcare providers' ability to communicate about end-of-life care.

Problems also exist at the post-graduate level. National guidelines limit the number of hours trainees may work to fewer than eighty per week, and because required tasks take up most of this time, useful activities such as observing senior attending physicians holding advance-care-planning conversations, or attending didactic courses on such planning, have lower priority. The explosion of "must-know" medical information in the last decade has further limited the time available for residency directors to offer communication training and education.

Perhaps because of this lack of training, many physicians are uncomfortable holding discussions about emotionally charged subjects, like the real nature of a patient's illness and the odds of dying from it, the length of time a patient may have left to live, and the full range of options for the goals of care. Yet patients need to be aware of all these factors if advance care planning is to be effective.

### **Advance Directives Are Unavailable and Non-Specific**

Research suggests that even when advance directives are completed, their effectiveness in aligning medical care with patient preferences has been marginal. Traditionally, patients have completed advance directives on their own, and these are filed or scanned into the medical record. It can be difficult for clinicians to access these documents because patients move rapidly among clinical settings, each of which may use different (and often incompatible) electronic medical record systems.

Most advance directives are completed in the primary care setting, yet care for patients in crisis, especially for those with advanced chronic illness, is delivered in the hospital. To access out-patient advance directives, hospital clinicians

must surmount many barriers. Although some states are developing online advance directive registries, more research into the use of online registries would be helpful. Electronic medical record vendors are working to make advance directives more available at the point of care, but until all assorted electronic medical record systems are interoperable (i.e., able to talk to each other), access to advance directives will remain a challenge.

The effectiveness of advance directives also has been limited because they are not specific or flexible enough to accommodate to the changing realities that illness brings to people's lives. Many people complete advance directives when they are healthy. This is useful, because it requires them to think through what kind of care they would want if they were to become seriously ill. But the best a healthy person can do in this situation is to imagine what being ill might feel like. This may or may not be an accurate forecast of the actual illness experience, which can occur years later. Many people think they will want one kind of care, but once they experience illness, they may change their minds. Also, once they have gained specific knowledge about various goals, they may decide, as an example, that they would want antibiotics for pneumonia, but would refuse being placed on a breathing machine. In complex clinical situations, simple advance directives completed years ago that say "no life-sustaining treatment" may no longer fit their needs.

### **The POLST Form: Beyond Advance Directives to Physician Orders**

Although advance directives often document what treatments patients want (or wish to avoid), they do not carry the authority of a doctor's order and, therefore, do not compel clinicians to follow the patient preferences listed on them. Physician Orders for Life-Sustaining Treatment (POLST) forms were created in 1991 to remedy this. Now used in forty-two states, eighteen of which comply with established national standards, POLST

provides a portable plan of care that standardizes patient–clinician communication, rather than simply documenting patient preferences, as do advanced directives.

POLST, known in some states as Medical Orders for Life-Sustaining Treatment (MOLST) or other names, must be signed by a designated clinician (and in some states, the patient) and be immediately recognizable throughout the community. This makes POLST actionable by physicians anywhere, plus first responders (paramedics, fire department personnel, police) and staff in emergency departments, hospitals, and nursing homes.

POLST forms are appropriate for patients with advanced illness, whom clinicians can identify by asking themselves, “Would I be surprised if this patient died within one year?” A “no” answer indicates that the patient’s illness is advanced. The POLST paradigm outlines what should take place after such patients are identified, as follows:

- A conversation should be held between clinician and patient about treatment options in light of the patient’s current condition;
- The patient’s preferences to receive or avoid treatment should be composed in the form of physician orders; and
- The patient should bring the completed POLST form when obtaining care in any setting.

The National Quality Forum has stated that, compared to advance directives, POLST forms more accurately convey end-of-life preferences and also lead to better adherence to patient choices by medical professionals. This does not negate the importance of advance directives, however—they still are useful because they allow patients to specify a surrogate decision-maker, whereas most POLST forms do not.

### **Clinician Payment for Advance Care Planning**

Interest in advance care planning and advance directives increased in 2016, due to the release

of advance care planning Current Procedural Terminology billing codes by the Centers for Medicare & Medicaid Services (CMS). These codes allow healthcare professionals to bill Medicare for care planning discussions with patients and their surrogates. Key provisions include the voluntary nature of these conversations, a primary focus on the advance-care-planning discussion rather than just document completion, and allowing non-physicians to bill Medicare, using the codes.

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### ***There is no gold standard for teaching medical students how to conduct advance-care-planning conversations.***

These new billing codes have encouraged the medical community to engage in better care planning with patients. A multi-pronged approach to improving advance care planning includes physician training and feedback on how to have such conversations, the use of patient decision aids to better inform them about advance directives, and better access to advance directive documentation in the electronic medical record to improve clinician access to these forms. Still, surveys done later in 2016 indicate that only a minority of clinicians has used these codes, which may indicate that it will take more than financial incentives to overcome clinician reluctance to initiate these discussions.

### **Making Advance Care Planning a Routine Part of Healthcare**

Advanced care planning has not yet become the standard of care. However, there has been recent progress on several fronts. What follows are some new clinical models and federal legislation that may support more widespread adoption.

**Independence at Home: bringing primary care to patients where they live**

Home-based primary care enables clinicians to assess and treat patients in the comfort and

safety of their own homes. The Independence at Home demonstration, authorized by Section 3024 of the Affordable Care Act, began in 2012 as a three-year project and was extended for two more years through September 30, 2017, by the Medicare Independence at Home Medical Practice Demonstration Improvement Act of 2015. Independence at Home provides Medicare beneficiaries who have multiple chronic illnesses and functional limitations with a complete range of primary care services at their place of residence.

Because home-based primary care gives clinicians more time to relate to their patients, it can encourage the kind of discussions that are essential for good advance care planning. Many Independence at Home enrollees have advanced illness; this intervention has been shown to improve participants' health and quality of life, provide greater patient and caregiver satisfaction, and reduce the need for hospitalization and associated Medicare costs. In the second year of the demonstration, Independence at Home practices saved more than \$10 million, or an average of \$1,010 per participating beneficiary.

#### The Advanced Care model

Independence at Home's results are encouraging, but even better outcomes might be achieved by focusing exclusively on a subset of the population—patients with advanced illness who may have about a year left to live. More than a quarter of all Medicare dollars are spent on care in the last year of life, and about a third of this final year's costs are accrued in the month prior to death, mostly for hospital treatment. Advanced illness occurs when one or more chronic conditions become serious enough that general health and functioning decline, treatment begins to lose its effect, and quality of life increasingly becomes the focus of care—a process that continues to the end of life. This is when advance care planning becomes most critical, because hospitalization rates tend to accelerate significantly.

Ideally, people who want to avoid becoming hospital patients should have a way of making these preferences known, so they can stay at home and remain comfortable. Beyond that, they need to be supported where they live to ensure that they can keep out of the hospital until the end of life, if that is their wish. Decades of work by hospice have shown this to be feasible, but hospice enrollments tend to happen too late in life to prevent many of these terminal hospitalizations, and many patients are never informed about hospice.

New Advanced Care systems now under development across the United States are changing the way care is delivered to patients with advanced illness. Trained staff are helping patients with advance care planning, instead of forcing clinicians to go out of their way to do so. One such program, Advanced Illness Management (AIM) at Sutter Health, was a 2012 grantee in Round 1 of the Health Care Innovation Awards, provided by the Center for Medicare and Medicaid Innovation. The Year 2 Report on this project showed that AIM achieved statistically significant improvements in quality and cost of care, with savings of \$6,047 per beneficiary in the last thirty days of life, compared to controls receiving standard care.

#### Federal legislative initiatives

The Personalize Your Care Act of 2016, sponsored by Reps. Earl Blumenauer (D-OR) and Phil Roe (R-TN), who is a physician, seeks to encourage more providers to have end-of-life discussions with seriously ill patients. The bill would promote increased public awareness of Medicare reimbursement for advance-care-planning counseling, establish an Advanced Illness Management and Choices Demonstration, and create policy requiring that advance directives be stored in electronic medical records for easy access by treating clinicians.

The Removing Barriers to Person-Centered Care Act of 2016, introduced by Sen. Sheldon Whitehouse (D-RI), would help coordinate care

among healthcare providers and place greater emphasis on the preferences of Medicare beneficiaries with advanced illness. The bill would establish a pilot program administered by CMS, consisting of twenty “advanced care collaboratives” of healthcare providers and community-based social service organizations. Each would receive an assessment and planning grant that would also cover improvements to electronic medical record systems and education

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### ***Advance care planning is a process— not a document.***

about documenting and communicating beneficiary goals and preferences. This planning phase would be followed by a three-year payment agreement with Medicare to provide coordinated, high-quality care to the target population. Existing regulations would be waived to allow patients to receive concurrent treatment and hospice services, to be able to enter a nursing home without a preceding three-day hospital stay, and to receive Medicare home health even if they are not homebound. The Act also would expand the authority of nurse practitioners to approve home health and hospice services.

### **Conclusion**

Advance care planning often is the deciding factor in determining whether patients will undergo only the tests and procedures they want, and pursue goals they wish to—no more and no less, at the right time and place—or receive treatment driven only by clinical factors. It is a process, not a document. Patients and their clinicians engage together to achieve fully informed consent through shared decision-making. Resulting patient preferences are

documented and made available to all clinicians who might encounter the patient in routine or emergency encounters. Currently, POLST forms, supplemented by advance directives that designate a surrogate decision-maker, may be the most effective way to make patient preferences accessible in order to drive care decisions.

To make advance care planning routine, as opposed to an add-on that taxes clinicians and patients, new care delivery models are needed. Independence at Home, Advanced Illness Management, and other Advanced Care models, as well as bills before Congress, are now advancing that agenda. Once advance care planning becomes a standard component of care, we can expect better quality and satisfaction—and lower costs. 

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# Aid in Dying: A Consideration of Two Perspectives

By Bill Novelli and Raca Banerjee

Aid in dying is a complex topic: presented here, a bit of background on the issue.

The following two articles by Barbara Coombs Lee and David Grube (page 39) and Burke Balch (page 42), which present supporting and opposing views of aid in dying, call for a brief introduction. The discussion around aid in dying is difficult: it evokes an extremely complex set of medical, emotional, and spiritual issues. While the articles cannot address all of these concerns, we hope readers will gain a better understanding of and perspective about differing sides of the issue.

The first article presents aid in dying as the ultimate expression of personal choice, values, and freedom, while the second argues that it may become a source of coercion by society or a care delivery system designed to conserve resources and capital.

In recent years, partially through the spread of stories such as that of 29-year-old Brittany Maynard, Americans are more aware of the growing array of options that may be available to them as they approach death. Consumer polling demonstrates that almost 75 percent of American adults believe individuals with serious illness should be allowed to terminate their lives (The Harris Poll, 2014).

Moreover, as of December 2016, six states, including Colorado, California, Vermont, Montana, Washington, and Oregon have legalized aid in dying for those who are seriously ill (Furr, 2016); Washington, D.C., may soon be added to that list (Orentlicher, 2016). According to research on current policies, there are three key stipulations designed to serve as safeguards to the individual: he or she must be certified to have only six months left to live, must be a mentally competent adult, and must administer the lethal prescription themselves (Orentlicher, 2016).

As the discussion around aid in dying grows, other questions arise. What is the role of providers in taking a stance or administering lethal medication? Organizations such as the American Public Health Association and the American Medical Student Association have supported aid in dying, while others such as the American Academy of Hospice and Palliative Medicine have taken a neutral position (Compassion & Choices, 2016). In addition, even though the American Medical Association has historically been opposed to aid in dying, the organization is

**→ABSTRACT** In this preamble to two opinion pieces on aid in dying, *Generations* Guest Editors Bill Novelli and Raca Banerjee introduce readers to this complex topic, which brings up strong medical, emotional, and spiritual issues. The Guest Editors hope, by presenting both an argument for and one against aid in dying, that readers will come to a better understanding of the issue and of the public's perception of it. The preamble provides background on the history and politics surrounding aid in dying in the United States. | **key words:** *aid in dying, lethal medication, Brittany Maynard, personal choice, care delivery system*

now considering conducting a study on end-of-life care options to re-examine its position on the issue (Pies, 2016).

This is a complex and controversial topic. Proponents of aid in dying suggest that it is the ultimate form of an individual's freedom of expression and belief—a construct that allows society to fully honor a person's dignity and wishes. On the other hand, opponents believe that enabling aid in dying may lead society along a slippery path that leads to care rationing and that may violate certain religious principles. As we approach this issue, we must think carefully

about how to balance respect for diverse values, faiths, and beliefs with respect for individual dignity and choice. 

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# Medical Aid in Dying: The Cornerstone of Patient-Centered Care

By Barbara Coombs Lee  
and David Grube

As more states authorize medical aid-in-dying statutes, they are effecting positive transformations around the end-of-life experience for patients and families.

In his brilliantly written book, *Being Mortal*, renowned surgeon Dr. Atul Gawande succinctly outlines the dichotomy between the amazing advances in twenty-first century medical technology and our society's unwillingness to confront death and the dying process and, more specifically, to learn about end-of-life care options. He notes these advances have not only led to increased longevity, but also to associated complications, prolongation of disease states, and suffering:

*Modern scientific capability has profoundly altered the course of human life. People live longer and better than at any other time in history. But scientific advances have turned*

*the processes of aging and dying into medical experiences, matters to be managed by healthcare professionals. And we in the medical world have proved alarmingly unprepared for it (Gawande, 2014).*

***'Scientific advances have turned the processes of aging and dying into medical experiences.'***

Medical ethics also have evolved in concert with this newfound technology and the acknowledgement of its sometimes negative impacts on patients. The tenets of patient autonomy and social justice have risen to become para-

mount ideals in the doctor-patient relationship, and a movement toward "patient-centered" or "person-centered" care has emerged. While the definitions of these terms differ, the common concept is that it is the patient's preferences, needs, and values that guide clinical decisions.

## **The Brittany Maynard Effect**

No instance exemplifies this concept more clearly than the case of Brittany Maynard, a young woman from California who in 2014 was dying of brain cancer. Even after undergoing a sophisticated surgery and numerous cancer treatments, her growing tumor was causing debilitating headaches and seizures. After exhausting all

**→ABSTRACT** There is a profound dichotomy between twenty-first century medical technology, which allows people to live longer lives than ever before, and our society's unwillingness to confront death and the dying process. This article addresses how authorizing medical aid in dying not only has the potential to transform the end-of-life experience for dying patients and their families, but also is a hallmark of the delivery of person-centered care. | **key words:** *medical aid in dying, patient-centered care, person-centered care, end-of-life options, death with dignity, Brittany Maynard, terminal illness, advanced planning*

treatment options to try to cure her cancer, Brittany left her home and friends and moved to Oregon to take advantage of the state's Death with Dignity Act. On November 1, 2014, she willingly self-administered aid-in-dying medication to end the unbearable suffering she was experiencing. Within thirty minutes of drinking the medication, Brittany died peacefully in her sleep with her family at her bedside.

Before she died, Brittany became a champion for the rights of terminally ill people. She had been informed of all her end-of-life care options by her medical team and in consultations with our country's best specialists. She knew what she wanted. She was an autonomous thinker, mentally capable, under no duress or coercion to make her choices, and incredibly brave and gracious. In videos she created, Brittany eloquently outlined her reasons for considering medical aid in dying. She wanted to die on her terms, with her family, in her home, with her poems and her songs. Having the medication available meant knowing she could prevent the very worst, the very last part of dying, if she chose.

Brittany's story exemplified person-centered care. It was an example of the medical system allowing the patient's values and priorities—including control over their own death—to be respected. This is why millions

of people worldwide responded so powerfully to Brittany's story, because through her actions, she firmly established that she, the patient, was making her own medical decisions. If healthcare systems truly want to deliver on their commitment to be "person-centered," then they must implement policies that respect the values of their consumers, including a patient's control over the circumstances of their looming death. In other words, adopting policies that support giving terminally ill patients the option of medical aid in dying is a hallmark of person-centered care.

### **A Palliative and Compassionate Medical Practice**

Medical aid in dying has been authorized in Oregon since 1997 (Oregon Legislature, 1997). During the past eighteen years, Oregon physicians have been allowed to discuss the full range of options in end-of-life care. As an unexpected consequence, hospice and palliative care in Oregon are unsurpassed in quality. State residents who consider medical aid in dying are almost always enrolled in a hospice program (93 percent), and an overwhelming majority (90.1 percent) are able to die at home, which is an avowed goal of most elderly and dying individuals (Oregon Public Health Division, 2016).

There has been no evidence of abuse of the Oregon Death

with Dignity Act, and no evidence that the financially disadvantaged, the uninsured, or persons with disabilities are at risk of coercion (Battin et al., 2007).

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### ***'Brittany Maynard's story exemplified person-centered care.'***

The medical aid-in-dying laws in Oregon (1997; 2016), Washington (2008), Montana (Baxter v. Montana, 2009), Vermont (2013), California (2015), and now Colorado (2016) have core safeguards, including strict eligibility requirements, to ensure the laws are safe and work as intended. Two physicians must concur that the dying individual has a terminal illness, with a prognosis of six months or less to live, is mentally capable to make his or her own healthcare decisions, and is under no duress to request an aid-in-dying prescription. Written as well as oral requests must be made by the patient, and may not be made by a surrogate. If a terminally ill individual presents to the clinician with any symptoms that would indicate impaired judgment, a third opinion from a mental health specialist is necessary to confirm mental capacity before a prescription can be written. Additionally, there are waiting periods before a prescription can be written.

Authorizing medical aid in dying also has the potential to transform the end-of-life experience for dying patients and their families. The law requires doctors to review all available end-of-life care options with their patients—from pain and symptom management to hospice and palliative care—before they can write a prescription for aid in dying. A study in *Journal of the American Medical Association* (Ganzini et al., 2001) credited Oregon’s Death with Dignity Act with contributing to better conversations between doctors and patients, better hospice

care, and better training of physicians on pain management and comfort.

### Access to Peaceful Dying and Peace of Mind

The act of obtaining an aid-in-dying prescription is palliative in and of itself. Approximately one-third of terminally ill people do not end up taking the aid-in-dying medication (Oregon Public Health Division, 2016), but just having it on hand—to know that they can take the medication if their suffering were to become unbearable, and that their physician respected and

honored their choice—is a great comfort.

Near the conclusion of his book, Dr. Gawande writes: “Life is meaningful because it is a story . . . and in stories, endings matter” (Gawande, 2014). In states where medical aid in dying is authorized, more people do not die because of medical aid in dying; but certainly, fewer people suffer. 

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# Death by Lethal Prescription: A Right for Older People—or Their Duty?

By Burke Balch

It is a slippery slope from legalizing the right to die to legally allowing surrogates to make that decision for incompetent patients.

The “right to die” is well on course to becoming a “duty to die.”

The Belgian Society of Intensive Care Medicine has declared the right of doctors to give lethal doses of sedatives to patients they claim have “no prospect of a meaningful recovery”—a decision that “should be discussed with and understood by the relatives (or the patient’s surrogate if one has been appointed),” but, “it must be made clear that the final decision is made by the care team and not by the relatives” (Vincent et al., 2014).

## *‘Is there a duty to die—a responsibility within the family unit—that should remain voluntary but expected nevertheless?’*

Derek Humphry, founder of the Hemlock Society (which, after name changes and a 2005 merger, has now become Compassion & Choices,

the primary organization advocating for U.S. legalization of lethal prescriptions), has argued:

*[T]he elderly [are] putting a strain on the health care system that will only increase and cannot be sustained. . . . The perception of the elderly as ‘greedy geezers’ may grow . . . [C]ommon sense dictates that avoiding . . . even treatment as inconspicuous as antibiotics, would save the nation money best spent elsewhere. . . . People with chronic conditions account for a disproportionately large share of health care use, both services and supplies. . . . Society is facing the tough questions that revolve around the effective—although costly—treatments that might give the elderly some added quality years but at the expense of younger, more vital individuals (Humphry and Clement, 1998).*

Asserting that “economics, not the quest for broadened individual liberties or increased autonomy, will drive assisted suicide to the plateau of acceptable practice,” Humphry asked, “Is there a

**→ABSTRACT** Death by lethal prescription is becoming a duty more than a right. Advocates of its legalization maintain it cannot validly be treated differently from rejection of life-preserving healthcare. Consequently, lethal prescriptions will be directed by surrogates for those unable to make healthcare decisions. Ultimately, health professionals will impose them against the wishes of patients and their families, as is now the case in Belgium. The view articulated by key legalization advocates that older people are unsustainably straining the healthcare system fosters the trend toward implementing a duty to die for older people, who are viewed as burdens. | **key words:** death by lethal prescription, surrogates, “right to die,” “duty to die”

duty to die—a responsibility within the family unit—that should remain voluntary but expected nevertheless?” (Humphry and Clement, 1998).

### **Equating Lethal Prescriptions with Refusing Treatment**

In Oregon, the first U.S. jurisdiction to legalize lethal prescriptions, Barbara Wagner, a resident with cancer, received a letter from the state’s Department of Health telling her that the state healthcare plan would not cover life-preserving drugs (which cost \$4,000 a month), but reminding her that she had the option to kill herself and the state would cover the cost of drugs for her to do so (about \$100) (James, 2008).

Advocates have long argued that use of lethal prescriptions is “essentially the same thing” as refusal of life-sustaining healthcare, and that as a matter of constitutional equal protection, no difference in their treatment can be justified (*Vacco v. Quill*, 1997). Although they lost in the Supreme Court in 1997, that was the premise of their case in *Vacco v. Quill*, which was developed and filed by Compassion in Dying (another former name for what is now called Compassion & Choices) (Compassion & Choices, n.d.).

Compassion & Choices’ current president, Barbara Coombs Lee, says, “I think a federal constitutional protection could be acknowledged at some point, but only after there is already a critical mass of states where it is already authorized” (Sanburn, 2015). She could well be right: with the membership of the Supreme Court changing and the largest population state, California, now on her side, it might take only another state or two, and a few years.

It bears notice that when a right to a lethal prescription is equated in all relevant respects with a right to refuse treatment, there is no basis for limiting its exercise to those with terminal illness, or to any particular set of ailments or disabilities, because under the doctrine of informed consent, one can essentially refuse any treatment, in any circumstance.

When in 1967 the Euthanasia Educational Council created the “living will,” its proponents argued with great persuasiveness that patients ought to have their wishes not to be “hooked up to machines” respected, not overridden by “paternalistic doctors” (Patients Rights Council, n.d.). When that notion had become widely accepted, then and only then was the argument advanced that when a patient is incapable of making healthcare decisions and has left no instructions, family members or other surrogates should be able to decide to withdraw life support. But when that concept, as well, had become imbedded in both law and popular opinion, the argument gradually shifted to the position that doctors and healthcare facilities should not be forced to provide “futile” care just because a patient or the patient’s family wanted life-saving measures.

As the New York State Task Force on Life and the Law has noted, “[A] treatment might be seen as futile if it does not offer what physicians consider an acceptable quality of life. For example, in one survey, a majority of physicians agreed that for a severely demented patient with Alzheimer’s disease, CPR would be ‘so clearly inappropriate or futile on medical grounds that physicians should be permitted to institute DNR status based on clinical judgment, without obtaining consent’ ” (New York State Task Force on Life and the Law, 1992). Forgotten were the diatribes against “physician paternalism”—the mantra became that doctors should not be forced to practice “bad medicine.”

### **“Physician-Assisted Dying”**

A similar path is being followed with respect to direct killing with lethal prescriptions.

In 2015, the Canadian Supreme Court legalized what it euphemistically called “physician-assisted dying” for anyone who “has a grievous and irremediable medical condition (including an illness, disease, or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her

condition.” “Irremediable,” the court stressed, “does not require the patient to undertake treatments that are not acceptable to the individual” (Carter v. Canada, 2015).

Coombs Lee hailed this decision, saying, “The eloquence of this decision will inspire everyone. . . .” (Kay, 2015).

While the ruling on its face only covered “a competent adult person who . . . clearly consents to the termination of life,” the court implied that it will later hold that surrogates have the right to kill people who cannot speak for themselves. After emphatically denying there is any relevant distinction between the rejection of life-preserving treatment and direct killing, stating that both hasten death, the court made a point of noting, “In some cases, [decisions to reject life-saving treatment] are governed by advance directives, or made by a substitute decision-maker” (Carter v. Canada, 2015).

Will surrogates in the United States be empowered to direct lethal prescriptions for people unable to speak for themselves who have never asked to die? Of people with dementia and cognitive decline who cannot make the choice for themselves, Coombs Lee has said, “It is an issue for another day, but is no less compelling” (Foster, 2014).

Indeed, given existing legal precedents, it is probable that in United States jurisdictions that have legalized lethal prescriptions for competent adults, it is only a matter of time before courts compel its extension to those of any age who are not competent to make such decisions for themselves.

The question of whether a state may constitutionally limit a right so that it is available only to competent people who themselves choose to exercise it voluntarily has already been addressed by numerous state courts in deciding whether food, fluids, or life-saving medical treatment can be withheld from an incompetent person, resulting in his or her death. With few ex-

ceptions, these courts have ruled, in the words of the Washington Supreme Court, that “an incompetent’s right to refuse treatment should be equal to a competent’s right to do so” (In re Grant, 1987, 1988). They have held that constitutional equal protection guarantees require that guardians must be permitted to “substitute their judgment” for the unknown preference of the incompetent patient, and thus be able to opt for her or his death.

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### ***Advocates have long argued that using lethal prescriptions is essentially the same as refusing life-sustaining healthcare.***

For example, in the California case *In re Drabick* (1988), the court held that because competent individuals can legally reject life-saving treatment, a conservator (the term used in California for a legal guardian) must be able to direct that his or her incompetent ward be allowed to die from discontinuation of food and fluids. The court explicitly rejected an argument that the state’s interest in protecting William Drabick from being non-voluntarily allowed to die justified preventing his conservator from directing that his food and fluids be stopped.

If no distinction is allowable between rejection of treatment, on the one hand, and lethal prescription, on the other, such precedents will assuredly compel recognition of a right of surrogates to direct lethal prescriptions for those unable to give directions themselves.

### **Healthcare Professionals’ Role in Lethal Prescriptions**

The asserted parallelism ineluctably leads to the further step, already in place in Belgium, of healthcare professionals imposing lethal prescription—even against the wishes of patient and surrogate.

In the context of raising his question of whether there is a “duty to die” by lethal prescription, Derek Humphry noted approvingly, “Several

hospitals in California have instituted a new policy that . . . allows doctors to deny aggressive medical treatment to patients whose cases they consider hopeless, regardless of the families' wishes. . . ." (Humphry and Clement, 1998).

Facility ethics committees now regularly consider whether or not to override the directions of patients or their surrogates to give them life-preserving healthcare—and they frequently refuse. As journalist Ann Wlazelek reported, "There has been a turnabout in medical ethics, one in which doctors no longer want to employ all that medical science has to offer to keep patients alive and families find themselves fighting for their loved ones' right to live (Wlazelek, 2004)." Readers of *Generations* journal who are involved in geriatric care can attest from personal experience to how common involuntary denial of life-sustaining treatment has become.

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***'We may accept that, for purely economic reasons, they can stop life after a period of three years of complete dementia, for instance.'***

Once lethal prescriptions become fully commonplace, and their use deemed equivalent to rejecting life-preserving treatment, there is no logical reason to suppose that the "duty to die" when one's quality of life is deemed too poor or when, particularly for older people, one's health-care costs are considered too high, will be limited to the involuntary withholding of medical treatment. Ethics committees will not just deny treatment, but also decree lethal prescriptions.

Dr. Pieter Admiraal, often called the "father of euthanasia" in the Netherlands, in 1987 told

the *Los Angeles Times*, "We can estimate that by 2020 or 2030 there will be the highest [proportion] of old people and the smallest amount of young people the world has ever known. We know already about the ratio of Alzheimer's disease in such an old population. We realize there will be demented patients by the tens of thousands. . . . I really think that [by then] we may accept that, for purely economic reasons, they can stop life after a period of three years of complete dementia, for instance. I can imagine that. . . . I don't believe we can prevent it" (Parachini, 1987).

Two decades ago, the New York State Task Force on Life and the Law (1994) concluded that the risks of legalization "would be most severe for those whose autonomy and well-being are already compromised by poverty, lack of access to good medical care, or membership in a stigmatized social group. The risks of legalizing assisted suicide and euthanasia for these individuals, in a health care system and society that cannot effectively protect against the impact of inadequate resources and ingrained social disadvantage, are likely to be extraordinary."

Current trends are vindicating that warning. Unless these trends are somehow reversed, the imposition of death by prescription of lethal drugs, regardless of the wishes of patient and family, is likely to become a key "solution" to the challenges of caring for a burgeoning population of older people. Those readers whose profession involves providing healthcare to older people may well be expected, as a standard part of their job, to participate in a new triage to implement, for the burdensome old, a duty to die. 

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# My Life, My Story: A Personal Experience with the Right Care, at the Right Time

By Amy Berman

One woman's story of her incurable cancer and the life-sustaining benefits of a care plan that honors her choices, values, and dignity.

*Editor's note: This article is adapted from Amy Berman's testimony delivered to the U.S. Senate Special Committee on Aging on June 23, 2016.*

**M**y name is Amy Berman and I am terminally ill. I was diagnosed five and a half years ago with stage IV inflammatory breast cancer, a rare form of cancer that has the worst prognosis. My cancer is not a lump that can be found on a monthly self-exam. By the time a red spot appeared on my breast, it had already spread to my lower spine. It is incurable cancer.

Roughly 90 percent of people diagnosed with breast cancer survive five or more years; unfortunately, the likely

course of the disease, according to the National Cancer Institute, is an 11 percent to 20 percent chance of survival to five years. This means it is highly unlikely that I would survive five years.

Yet here I am five and a half years following the diagnosis. I feel like I look, great. I work full time. I travel and enjoy my family and friends. I haven't been hospitalized once. I am a walking triple aim of better health and better care, and I have saved more than a million dollars to date. But the care that I receive is the exception.

At the beginning, I went to see two very different oncolo-

gists. One oncologist wanted to throw everything at the cancer. He heroically suggested the most intense chemotherapy, followed by a mastectomy, many courses of radiation, then

more intense chemotherapy. He admitted that it would not cure the disease but said, "This is what I do for all my patients." He never asked me a single question about what I was hoping for. He never discussed the futility of his approach or other treatment options. He wanted to do a

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***One doctor wanted to do a 'Hail Mary' pass on my body; he wasn't going to live with the consequences of this care—I was.***

**→ABSTRACT** This article is adapted from Amy Berman's 2016 testimony to the U.S. Senate Special Committee on Aging, on how she chose palliative care over invasive, non-productive treatments when diagnosed with terminal stage IV breast cancer. Berman emphasizes the importance of care planning, building a sufficiently trained support workforce, and successful models of care, including community-based palliative care. Berman says she embodies the triple aim: enjoying better health, better care, and saving more than a million dollars. | **key words:** *palliative care, triple aim, Respecting Choices, Independence at Home, POLST, Vital Talk, The Conversation Project, and the Coalition to Transform Advanced Care*

“Hail Mary” pass on my body. He wasn’t going to live with the consequences of the care. I was.

I went to another oncologist who talked to me about my diagnosis, the likely course of the disease, and treatment options. She shared openly what she knew and asked me what I hoped for. I told her that I wanted the Niagara Falls trajectory: I wanted to feel good and then drop off the cliff. I told her that I wanted to maximize my good days and not aggressively push for more bad days.

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***‘I am a walking triple aim of better health, better care, and I have saved more than a million dollars to date.’***

She said I could opt for treatment (medication) that had the least amount of side effects, which could help to hold back the cancer and allow me to continue to feel well. My doctor said I didn’t need to have a mastectomy because the cancer was already floating throughout my body. The mastectomy wouldn’t get rid of the cancer. It would work against my goal of holding onto the life that I have. The surgery would be debilitating, make me miss work, cause pain and possibly swelling of the arm. This is everything I told her I wanted to avoid.

My mother was with me as I went on these visits. She participated in the conversations with me and my care team.

She fully understands and supports my choices. She is my healthcare proxy and I am hers. I completed my proxy with a social worker at my medical center just after diagnosis.

But perhaps the most important aspect of my care, the reason that I am doing so well despite being seriously ill, is palliative care.

Palliative care is the best friend of the seriously ill. It is an extra layer of support that goes along with the care provided by my oncologist. Studies have

shown that when palliative care is added at the beginning of a serious illness,

that people feel better and live longer. My palliative care provider has helped me determine what care to opt for and addressed my pain and symptoms. The team-based care also addresses the needs of the family, care coordination, and even spiritual needs.

I am terminally ill. But I also have a professional role as senior program officer at The John A. Hartford Foundation in New York City, where I lead efforts to develop, test, and spread evidence-based models of care that improve the care of older adults. We are longtime funders of palliative care, supporting the Center to Advance Palliative Care, the leading national resource for the field of Palliative Care, for more than

a decade. We also fund the leading efforts in care, training, and public engagement. These efforts include Atul Gawande’s and Susan Block’s Serious Illness model; Respecting Choices; Home-Based Primary Care (Independence at Home); National POLST (Physician Orders for Life-Sustaining Treatment); Vital Talk; The Conversation Project; and the Coalition to Transform Advanced Care, also known as C-TAC.

I want to touch upon three key areas of interest to me—the importance of care planning, the workforce, and models of care, including community-based palliative care.

Care planning is key to providing the right care and avoiding the wrong care for the seriously ill person. It is more than just advance care planning and the end of life. Care plans include goals of care conversations over time and specifically before critical choices about treatment need to be made. The seriously ill very often aren’t told their prognosis. You can only make reasonable decisions and plan for the future when you know how ill you are and the likely course of the disease.

A survey of 2,000 physicians published in *Health Affairs* found that a startling two-thirds of the physicians reported that they either gave a rosier prognosis or were not truthful with their patients (<https://goo>.

gl/zxDEiK). Similarly, less than 50 percent of people living with Alzheimer's disease or their family caregivers are informed of the diagnosis, according to a 2015 article in *USA Today* (<https://goo.gl/PMWd6R>).

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***The most important thing we could do is to create a mechanism to cover community-based palliative care—the kind of high-value care we all desire.***

Understanding where you are in terms of your overall health is one of the key components to your participation in decisions about your care. It astounds me that we have more protections around full disclosure when buying a home than when we are treated for serious illness.

Our workforce needs experts to support the care of the seriously ill and they must themselves be competent in the care for this population. We do not have a sufficient number of palliative care physicians and

nurse practitioners to care for the seriously ill demographic.

Did you know that we pay for graduate medical education slots for cardiologists, neurologists, even plastic surgeons, but not one slot for palliative care?

We have a rapidly aging society with an older demographic that is doubling. Yet we have not

dedicated a single slot to train our palliative care workforce, a workforce that improves the quality of life, length of life, and decreases unnecessary high-cost care, such as hospitalization and nursing home placement, for the seriously ill.

There are a number of models that address the complex needs of people battling serious illness and approaching the end of life. The most important thing we could do is to create a mechanism to cover community-based palliative care. This proactive

care is the kind of high-value care we all desire. Yet palliative care remains largely only available in the hospital, and is an essential part of good inpatient care. It is care you need when everything goes wrong. But we need a proactive approach to care that avoids unnecessarily high-cost care that people want to avoid.

For me, my cancer continues to advance. I recently started a third treatment after the first two treatments failed. This is an ominous sign. Yet I continue to feel great and live a productive and happy life, thanks to palliative care.

I sincerely hope that we can all work together and move swiftly to further these aims and improve the care of the seriously ill—and please, let's make this happen in my lifetime. 

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*Amy Berman, B.S.N., R.N., L.H.D., is senior program officer of The John A. Hartford Foundation in New York City.*

# Caregiving at the End of Life: The Challenges for Family Caregivers

By Barbara A. Given  
and Susan C. Reinhard

Family caregivers face considerable challenges providing end-of-life care for older loved ones; this primer can help them provide the best care—and self-care—possible.

Improving the quality of care for patients at the end of life has become a national concern, as well as a clinical objective, for healthcare professionals. Increasingly, access to and quality of care are receiving the attention of policy makers and influencing public debates. There have been numerous national reports and books about the end of life, such as *Approaching Death: Improving Care at the End of Life* (Institute of Medicine [IOM], 1997); *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life* (IOM, 2014); and *Death and Dying in America* (Fontana and Keene, 2009). Best-selling books include *The Good Death: An Exploration of Dying in America* (Neumann, 2016); *When Breath Becomes Air* (Kalanithi, 2016); *Being Mortal: Medicine and What Matters in the End* (Gawande, 2014); and *The Last Lecture* (Pausch, 2008).

The National Quality Forum (2012) defines end-of-life care as comprehensive care that addresses medical, emotional, spiritual, and social

needs during the last stages of a person's terminal illness. Much of this care is palliative or supportive, and provided when life-prolonging treatment and interventions are no longer appropriate.

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## ***Caregivers need support and guidance in processing their emotions and fears around end-of-life care.***

Significant attention has been appropriately focused on patient needs at the end of life. But family members are integral to the end-of-life care experience and responsible for much of the care required. Family caregivers actively participate in the decisions that are made, whether the patient's death occurs in the hospital, hospice, nursing home, or home. Healthcare professionals' awareness of and concern for family caregiver involvement are critical.

We are making advances in palliative, hospice, and end-of-life care, yet patients and fam-

**→ABSTRACT** In recent years, end-of-life care has been receiving attention in the lay and professional press. Integral to the concerns for patient-centered supportive care is the need to focus on the family caregiver, as they are directly involved in the patient's care. This article describes relevant challenges for the family caregiver, including information about types of care, scheduling and logistics, patient physical care, including symptom management, caregiver emotional and physical health, advance directives, coordination of care, and communication. It concludes by imagining a better system of end-of-life care for patients and caregivers. | **key words:** *caregivers, older adults, end-of-life care*

ilies continue to have concerns around cost, lack of compassion and dignity, fragmented care, pain and discomfort, and a drawn-out dying process. Improving access to and quality of end-of-life care is becoming increasingly important as the number of older adults increases and individuals are living longer lives.

### **The Challenges of Family Caregiving**

In the United States, a person's death often is preceded by time periods when family caregivers are directly involved in their family member's care. Caregiver involvement shifts to end-of-life care as the person's disease progresses and they become more dependent. Yet little attention has been paid to the family members and their role in this transition.

Family members and-or healthcare professionals often delay having discussions and making decisions about the goals of care when a patient's condition becomes progressively worse—when care goals might shift to palliative and supportive care. Making the decision to stop curative care and change to comfort and supportive care is one of the most difficult for patients, family caregivers, and healthcare professionals. Caregivers need support and guidance in processing their emotions and fears around these decisions.

Family members also need information about the patient's changing condition, about managing end-of-life symptoms, about the dying process, and guidance in giving care and support. Caregivers need emotional support for their loved one, as well as for themselves, as they face uncertainty about the end-of-life process. Although resources for hospice, palliative care, and end-of-life options exist, care often remains fragmented and family caregivers may not benefit from such information because of the multiple care settings, transitions, and decisions to discontinue therapeutic or life-prolonging care.

#### **Caregiver scheduling and time stress**

The rapidity of a patient's physical decline, length of illness, and uncertainty about care

affect the caregiver's personal time, disrupting schedules. Adult-child caregivers may also be taking care of children, working outside the home, and having other social roles. For employed caregivers, end-of-life care responsibilities and care coordination affect work responsibilities. They may need to take personal time, vacation time, or family leave to perform or oversee patient care activities.

Patients have complex medication and-or treatment regimens as they become more physically dependent and require more direct care and assistance. The complexity and "hours of care" change as the patient becomes more dependent. For some caregivers, it is constant, daily around-the-clock care; for others, caregiving is equivalent to a part-time job (twenty hours per week) or it might be only a few hours per day (Reinhard, Levine, and Samis, 2012).

The scheduling and care logistics for family caregivers can be overwhelming, given the large number of medications to manage, along with handling treatments such as oxygen, injections, dressings, and catheters. Caregivers also frequently juggle hospice care, homecare, and physical therapy.

As caregivers provide this wide variety of care, they become more vulnerable to emotional stress and physical strain. Many caregivers express concern over a burden on their time, as they must often adjust their schedules and relinquish valued personal activities (Burton et al., 2012). Caregivers need conversations with health professionals about patient care and about self-care (Nielsen et al., 2015; Kramer and Boelk, 2015). And health professionals need to be aware of how these factors affect the caregiver and overall patient care, and offer supportive care and referrals to community services (Rabow, Hauser, and Adams, 2004; Kramer and Boelk, 2015).

#### **The complexities of care management**

Patients receiving complex intensive medical care as death nears often rely on family caregivers as the one consistent care provider (Rabow,

Hauser, and Adams, 2004). Family members are expected to perform this care, maintain sophisticated equipment, and make critical decisions, often without the support of the healthcare system. Caregivers report low preparedness for end-of-life care and often indicate they do not have the knowledge and skills needed for providing this type of care. Given the added emotional stresses related to the end of life (i.e., worry, anxiety, and depression), this phase becomes an especially difficult time for caregivers, who may be at risk of becoming ill as care demands exceed their resources and capacities (Burton et al., 2012).

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***For some people, caregiving is daily and around the clock—for others, it is equivalent to a part-time job.***

Caregivers often are thrust into their role with no training or support to provide physical care to patients, yet they are expected to provide complex medical care tasks, administer medications, provide direct physical care, and manage symptoms (National Alliance for Caregiving and AARP Public Policy Institute, 2015). Care tasks include dressings, catheters, skin care, and oxygen supplementation, as well as turning, moving, and lifting the person. They may need to bathe, feed, toilet, and dress their loved ones. Caregivers with little preparation for this role can end up with low confidence and feelings of incompetence in their ability to provide care, which adds to caregiver distress.

Pain and other symptom management is a central component of end-of-life care (Lorenz et al., 2008; Wilkie and Ezenwa, 2012). As patients near the end of life, they experience high symptom burden that requires additional tasks to achieve comfort. It can be uniquely challenging to provide comfort for hard-to-control symptoms such as dyspnea, pain, and-or confusion. Anorexia also poses a challenge for caregivers, as many believe if the pa-

tient eats, their life will be longer; a decision to refuse food may be the patient's acceptance that death is imminent.

Poor communication and conflict with the healthcare team often revolve around issues of pain and symptom management. Family members need help to adapt to changes in the level of care and modify the care plan when disruptions or unplanned events occur (National Alliance for Caregiving and AARP Public Policy Institute, 2015). They also need education and training about the various potential illness trajectories, patterns of pain, and other factors of symptom management. Family caregivers become very concerned about unmanaged pain; they fear giving too much or too little medication. Caregivers also fear and misunderstand medication side effects and addiction (Demiris et al., 2010; Dy, 2010; Wilkie and Ezenwa, 2012).

***Caregiver stress, and emotional and physical health***

The caregiver role may lead to considerable psychological and physical morbidity. Caregiver responses to providing care depend upon the complexity of care, changes in the patient's condition, and concern over performing tasks safely. Caregiver distress, grief, burden, and depression are accentuated by family conflict over decisions made or not made, uncertainty, or past family conflicts. At the end of life, caregivers liken stressful situations to a rollercoaster ride, as patients' conditions fluctuate between crisis and brief periods of improvement. The prolonged nature and extensive sets of tasks and changes, plus emotional stressors, can cause caregiver exhaustion (Nielsen et al., 2015). As well, distress from realizing the patient is at the end of life may interfere with caregivers' abilities to make decisions and deliver quality care for their loved ones (Kramer and Boelk, 2015). Caregivers need guidance and counseling so they can continue with patient care (Lorenz et al., 2008).

When the caregiver is an older person who has a chronic disease, it may be difficult for him or her to provide care. A caregiver's diabetes, heart failure, or hypertension may be exacerbated. The physical health risk to caregivers can manifest in symptoms of sleep disturbance, gastrointestinal disorders, fatigue, loss of strength, and weight loss. Healthcare professionals need to regularly assess caregivers' healthcare needs, the resources at their disposal, and their capacity, so that caregivers can continue to provide care.

Caregivers often indicate their health has gotten worse as a result of caregiving and the associated physical strain (National Alliance for Caregiving and AARP, 2015). As hours and care demands increase, caregivers become more isolated at a time when they most need support. Helping family members to understand the expectations of the patient's status of care during this phase is as important as it is for caregivers to accept assistance and support.

Caregivers also may be faced with a financial toll when families have high out-of-pocket costs for services and equipment at the end of life. These costs can include expensive prescription drugs, equipment, home healthcare services and health assistants, household help, and adjustments to the home's physical environment. Employed caregivers may see a loss in income and benefits. Care coordination efforts should consider the financial impacts and refer caregivers to resources and benefits so they can maximize their use; for example, family medical leave, when available, provides twelve weeks of unpaid job protection.

#### Care transitions and care coordination

Formal care support in hospitals or hospice often occurs after weeks, months, or even years of family caregivers having provided care through an evolution of chronic health problems. And care at the very end of life can be complicated if patients are hospitalized in an acute-care setting where curative, not palliative,

care occurs (Gallagher and Krawczyk, 2013). In situations when a disease such as cancer progresses, the oncology team may return the patient care to his or her primary care provider, which means caregivers must work with new and-or different healthcare providers who have not been a part of the patient's cancer care treatment team.

The challenge is to effect continuity of care across transitions. Thus, care coordination among and between providers, the patient, and family is crucial. Transitions between multiple settings cause disruptions and fragmented care: referrals may not be made, follow-up can be delayed, and information such as advance-care-planning documents and records of other patient preferences may be lost. The patient's condition may destabilize and deteriorate as he or she transitions between settings such as urgent care, emergency rooms, intensive care units, or long-term-care units.

An important component of the intensive care unit for patients at the end of life should be caring for family members because of the changes in the patient's condition and the uncertainty the family caregiver faces (National Quality Forum, 2012).

The support caregivers need and patients' preferred care settings may change over time, thus professionals should continue to assess these changing preferences. One model of care for caregivers is the Medical Home (see section on page 54), which offers coordinated primary care to foster coordinated patient- and family-centered care (IOM, 2014).

#### Strategies, Supports, and Advocacy for Caregivers

Caregivers can have positive experiences at the end of a loved one's life—feelings of self-esteem, feeling uplifted, and realizing their essential role in the patient's care. High-quality patient-centered (family-centered) care at the end of life should reflect patient and family values, goals, and informed preferences. The following sec-

tions outline strategies, supports, and advocacy for family caregivers and care recipients.

#### Moving communication upstream: advance care planning

Having advance care directives in place helps families cope with their emotions, and helps them to convey patients' preferences to health-care professionals. Professionals, patients, and caregivers need to work together to honor decisions about the patient's preferred end-of-life path. These conversations prevent unnecessary conflicts and non-preferred decisions. Advance care plans that translate the patients' values and goals, and identify patient preferences, should be recorded in electronic medical records to support the family caregiver and promote continuity of care when transitions occur (IOM, 2014). Poor communication between patients, caregivers, and healthcare professionals about treatment wishes may still occur, but having a written advance directive gives family members leverage.

#### Communication between all parties is key

Communication between family members and healthcare professionals regarding who is responsible and accountable for end-of-life care remains a challenge. Promoting and facilitating open communication to foster patient- and family-centered shared decision-making, and advance care planning is essential. Ethnic and cultural differences should be acknowledged. Family members' decision-making strategies around options of care, location, and preferences should take into account cultural, ethnic, and religious preferences. The earlier these discussions can occur, the better, so when there are unexpected changes in a patient's condition, discussions have already happened and decisions have been made.

#### The physician's part in communication

Healthcare professionals often are reluctant to discuss end-of-life care, but now that Medicare

will reimburse physicians and nurses to hold advance planning discussions, this may change. Professionals will have the opportunity for training and skill-building activities so they can be effective and compassionate during difficult conversations; if they develop these skills, they are more likely to have these discussions.

#### Care supports and options: discharge plans, the Medical Home

Improving care for people with advanced illness can lead to improved end-of-life care. Many care transitions across settings can occur due to deteriorating illness and can cause care fragmentation and discontinuity, which bring disruption and lack of closure to families.

Discussing discharge plans of care with family members at hospital discharge is now law in thirty-one states under the CARE Act (Reinhard and Ryan, 2016). For patients at the end of life, discharge plans with information and instructions for caregivers could include comfort care. Health technologies and informatics would be useful to support caregivers with discharge information for end-of-life care. Electronic support groups and communication with healthcare professionals about the patient using "patient portals" supports caregivers (Demiris, Parker Oliver, and Wittenberg-Lyles, 2011). Team meetings can be run via video, to problem solve and to provide caregiver support.

Considering the primary care provider or the Medical Home as the coordinator of end-of-life care could facilitate patient- and family-centered end-of-life care. The Medical Home is a model for organizing primary care; it respects the patient's wants, needs, and preferences, and provides them with the education and support they need to make decisions and participate in their own care.

Family caregivers should be engaged partners in the patient's plan of care and considered as members of the healthcare team. Our nation's healthcare system should aim for fewer procedures, fewer acute care admissions, less inten-

sive care, and fewer care setting transitions, and put more focus on supportive and comfort care. Doing so could result in more constructive and compassionate ways to respond to the social, psychological, and spiritual needs of both the patient and family members (Rabow, Hauser, and Adams, 2004; Meier et al., 2016; National Quality Forum, 2012).

#### Comfort and supportive care standards, guidelines, and measures

Our country needs quality standards, guidelines, and measures for comfort and supportive care so we do not over-treat, but instead allow patients and families to decide on the care they prefer. Professional societies should be challenged to develop standards and measures of care for end of life. Guidelines for assessment are necessary to determine when to withdraw therapeutic treatment and move to supportive care. The American Academy of Hospice and Palliative Medicine and the Hospice and Palliative Nurses Association are working together to develop and use quality measures that reflect patient and family goals and preferences to ensure that individual values, goals, and preferences are considered.

#### The need for public education

As a nation and a population, we are beginning to have general and broad conversations about end of life, and about needed care, but when we actually provide care for an individual, many areas of concern remain. Care choices are not made clear to patients and their families, and care fragmentation occurs.

Public education at the national level about end-of-life and supportive care is necessary. And there should be a clearer understanding of the benefits of appropriate end-of-life care. We must stop treating death as a medically treatable condition. Media outreach, community education, and community awareness programs should be used to reach individuals to discuss how to have these conversations and make in-

formed decisions about end-of-life treatment and care.

Health systems need to be required to describe what services and supports are available in their communities. Expanding the repertoire of skills, resources, and services available to families for end-of-life care is vital for healthcare systems as community outreach support. Community education programs could help citizens understand care choices and be better informed when faced with end-of-life care decisions.

#### The need for professional education, legislation, and regulations

A better future will require education for professionals as well as for the public. Educational institutions, credentialing groups, and regulatory groups need to establish training and credentialing for those who care for patients with serious and life-limiting illness and their families. Professionals need training and expertise so they can be comfortable with these conversations.

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### ***For patients at the end of life, discharge plans with information and instructions for caregivers could include comfort care.***

Along with the education of professionals and the public, we need additional legislation and regulations. Both Medicare and Medicaid have a hospice benefit that is not used effectively. We need financial incentives to reduce the current use of emergency departments and intensive care services for patients at the end of life, and to reduce the use of unnecessary medical services and shift to supportive, comfort, or end-of-life care.

#### The need for research, cost analysis, and assessments

Research is needed to provide evidence on strategies that work to engage family caregivers in

end-of-life care to make it a positive experience. More research is needed on caregivers' needs, behaviors, health risks, success in performance, interaction with professionals, and crucial support services from the view of the caregiver (IOM, 2014). And we need cost-effective analysis to find the most efficient method for the formal and informal systems to work in partnership to provide a good end-of-life experience for patients and families.

Since 2014, hospices were required to have a “hospice item set” to measure quality, including pain assessment, dyspnea care, and treatment preferences. The Centers for Medicare & Medicaid’s Hospice Item Set collects data on opioids (with bowel regimen), pain assessment and screening, dyspnea screening and treatment, and treatment preferences (National Quality Forum, 2016). Analysis is needed to determine if there has been improvement; care improvements in these areas would be very helpful to caregivers.

## Conclusion

Support from healthcare professionals is necessary to ensure that more family caregivers have a positive experience with providing advanced illness and end-of-life care. We should maintain quality of life within the constraints of advancing disease and consider the family caregiver as part of the focus of care—together they are the unit of care (IOM, 2014).

As previously mentioned, Medicare had agreed in 2016 to pay physicians and advanced practice registered nurses to provide end-of-life counseling for beneficiaries and their families. By engaging patients and caregivers in understanding their options, professionals can encourage a team approach to end-of-life care. By emphasizing communication and counseling, perhaps Medicare can reduce some of the unnecessary and often unwanted care (Teno et al., 2013).

Improving access to and quality of end-of-life care are becoming increasingly important as the number of aging patients increases and they live longer. In considering their care at the end of life, healthcare professionals should also care about family caregivers. Healthcare professionals have an opportunity to support the profound end-of-life experiences of family caregivers: they can foster dignity at the end of life for both patients and caregivers. 

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# Lessons from the Hospice Benefit for Advanced Illness Care

By Perry G. Fine  
and Malene S. Davis

The Medicare Hospice Benefit was revolutionary at inception, but it is time for the Benefit's next iteration.

By most measures of benefit and cost, hospice has been a successful experiment in end-of-life care. As this model of comprehensive far-advanced illness and terminal care approaches half a century of practice in the United States, it is time to reflect on the many lessons learned from this experiment. In particular, we should look back at the Medicare Hospice Benefit (MHB), which was legislated a decade after the concept of hospice care migrated from England to North America; the MHB has paved the way for all Medicare beneficiaries to access hospice care. In large part because of this payment stream, hospice has moved beyond its roots in end-stage cancer care and the imminently fatal HIV-AIDS epidemic of the 1980s, and now provides end-of-life care to Medicare beneficiaries facing most causes of death.

Ironically, due to more recent de-limiting interpretations of eligibility for the MHB, one of the most common causes of death in frail elderly individuals—non-specific multi-system failure,

which is clinically referred to as progressive debility, or failure to thrive, among other designations—has been disallowed under Medicare as a hospice diagnosis. Notwithstanding this and other serious glitches in the current system, since the MHB's inception, the numbers of patients and their families who have benefited from hospice care has grown dramatically (National Hospice and Palliative Care Organization, 2015).

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***A common cause of death in frail elderly individuals—non-specific multi-system failure—has been disallowed under Medicare as a hospice diagnosis.***

As we examine positive and negative lessons learned, we see that this model of care provides an empirically proven and exceptionally strong foundation from which to construct a more cogent and coherent advanced illness and end-of-life healthcare system. Because social attitudes, demographics, and clinical and economic circumstances have changed so

→**ABSTRACT** Since its inception thirty-five years ago, application of the Medicare Hospice Benefit has improved the quality of life of millions of people with terminal illnesses, while supporting their families' caregiving and emotional needs. This article reviews the origins and progression of hospice care, including the difficult issue of ever-increasing prognostic uncertainty. The authors conclude that this important benefit for patients living with chronic progressive illnesses needs to be updated to assure more timely access, less regulatory ambiguity, and more seamless integration into mainstream healthcare delivery systems. | **key words:** *advanced illness care, end-of-life care, hospice, Medicare Hospice Benefit*

dramatically since the MHB's inauguration, it is time to update the statutory and administrative terms and conditions of this entitlement. In this article, we will synthesize our reflections from our careers spanning the past thirty years working within the MHB into a handful of vital lessons, from which we envision a sanguine future for comprehensive and coordinated advanced illness care.

### **Lesson One: The Hospice Benefit Is Effective**

The hallmarks of hospice, under the aegis of the MHB, are its at-risk, per diem, and capitated-payment structure and its interdisciplinary team approach. The interdisciplinary team model of care distinguished itself from conventional healthcare delivery structures as a more coordinated means of providing comprehensive patient-centered care.

The more typical multidisciplinary group of healthcare professionals working as a team generally functions separately, in serial fashion. Although overall objectives may jibe, team members rarely work or meet together, and even less frequently interact with the intent to overlap and interweave skill sets and care plans to arrive at patient- and family-centric goals and objectives. The multidisciplinary team is characterized by defined roles and maintains (even guards) boundaries around those roles. Interdisciplinary teams require cooperation and communication as a fundamental necessity to patient-centered care.

With great adherence to the team-based paradigm over the years, when applied to care for patients with life-limiting disease and their families, the interdisciplinary team model has consistently derived the desirable outcomes of safe and comfortable dying, self-determined life closure, and effective bereavement; as such, this model of care migrated upstream to chronic care, most notably as the Chronic Care Model (CCM).

In a *Health Affairs* article, Coleman et al. (2009) write, “Chronic diseases are now the

major cause of death and disability worldwide, responsible for 59 percent of deaths and 46 percent of the global burden of disease. Despite advances in the effectiveness of treatment, research shows that patients frequently do not get the care they want or need. The CCM is designed to help practices improve patient health outcomes by changing the routine delivery of ambulatory care through six inter-related system changes meant to make patient-centered, evidence-based care easier to accomplish. The aim of the CCM is to transform the daily care for patients with chronic illnesses from acute and reactive to proactive, planned, and population-based. It is designed to accomplish these goals through a combination of effective team care and planned interactions; self-management support bolstered by more effective use of community resources; integrated decision support; and patient registries and other supportive information technology (IT). These elements are designed to work together to strengthen the provider-patient relationship and improve health outcomes.”

The CCM was based on initial evidence from a review of interventions to improve care for chronically ill populations. These evaluations showed—and a subsequent review (Sendall et al., 2016) has confirmed—that multi-component practice changes in the following four categories led to the greatest improvements in health outcomes: increasing providers' expertise and skill; educating and supporting patients; making care delivery more team-based and planned; and making better use of registry-based information systems. With the exception of the latter component, these categories seem to have been most realized within the Medicare population through the application of the MHB to those with terminal illnesses.

Although patients and families seem roundly satisfied with hospice care, formal quality measure reporting under the MHB is a recent addition to its regulations. The Affordable Care Act of 2010 (ACA) mandated the Hospice Quality

Reporting Program in Section 3004, which directs the Secretary of Health and Human Services to establish quality reporting requirements for hospice programs.

Quality measures calculated using the Hospice Item Set (HIS) include the following seven indicators: Patients Treated with an Opioid Who Are Given a Bowel Regimen; Pain Screening; Pain Assessment; Dyspnea Screening; Dyspnea Treatment; Treatment Preferences (preferences for life-sustaining treatments); and Beliefs/Values Addressed (Centers for Medicare & Medicaid Services [CMS], 2016).

Recently, a larger set of recommended quality indicators was published by the American Academy of Hospice and Palliative Care and the Hospice and Palliative Nurses Association (Dy et al., 2015). This set of ten measures includes the following: Comprehensive Assessment; Screening for Physical Symptoms; Pain Treatment; Dyspnea Screening and Management; Discussion of Emotional or Psychological Needs; Discussion of Spiritual/Religious Concerns; Documentation of Surrogate; Treatment Preferences; Care Consistency with Documented Care Preferences; and Global Indicator of Patient/Family Perceptions of Care.

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***For certain diagnoses, life expectancy is longer for those receiving hospice care—on average, up to a month longer.***

It likely will be several years before these measures of quality care will become normalized within hospice practice, much less validated and refined. But they provide an important step forward in providing the public with some potentially valuable comparative information from which to make informed choices about hospice programs.

In the interim, a retrospective satisfaction survey exists, the Family Evaluation of Hospice Care, as well as several instructive studies evaluating satisfaction with interdisciplinary hos-

pice and palliative care. For instance, bereaved family members are more likely to highly rate overall satisfaction with hospice services if they were regularly informed about their loved one's condition, if they perceived that emotional support was provided, if they received accurate information about treatments, and if they were able to readily identify one nurse as being in charge of their loved one's care (Rhodes et al., 2008).

A previous study evaluating almost 30,000 surveys suggested that interdisciplinary hospice care needed to better attend to families' needs for support and for communication and care coordination (Connor et al., 2005). It remains to be seen whether or not the implementation of HIS measures will match and fulfill patient and family perceptions of quality care.

In a prospective study involving 298 patients with an anticipated life expectancy of less than a year and a recent hospitalization, Brumley et al. (2007) evaluated the effects of an interdisciplinary team providing pain and symptom relief, patient and family education and training, and an array of medical and social support services (i.e., the equivalent of hospice care, but in advance of a six-month prognosis, as delimited by the MHB) compared with usual care.

The investigators found that patients randomized to in-home palliative care reported greater improvement in satisfaction with care at thirty and ninety days after enrollment ( $P < 0.05$ ), and were more likely to die at home than those receiving usual care ( $P < 0.01$ ). In addition, patients receiving in-home palliative care were less likely to visit the emergency department ( $P = 0.01$ ). Costs of care for this group were also lower; we will explore this metric of interdisciplinary advanced illness care in much greater depth in the following section.

In one of the first systematic reviews evaluating outcomes of the interdisciplinary team model of palliative care, Hearn and Higginson (1998) evaluated the findings of eighteen studies,

including five randomized controlled trials. They concluded that this approach to care of advanced cancer patients leads to greater patient and family satisfaction, improved symptom control, less inpatient hospital days, lower overall health-care expenditures, and patients' deaths taking place in their preferred setting.

The interdisciplinary care model also affects life expectancy. Temel et al. (2010) showed that early palliative care among patients with metastatic non-small-cell lung cancer led to significant improvements in mood and overall quality of life, less aggressive care at the end of life, and longer survival. In a study comparing hospice and non-hospice patients from matched cohorts of the Medicare data set who die within a three-year window, Connor et al. (2007) found that for certain diagnoses (i.e., congestive heart failure and lung, pancreatic, and, to a lesser degree, colon cancer), life expectancy is longer for those receiving hospice care—on average, up to a month longer. For other diagnoses, life expectancy was not different among the groups.

The question of survival is an important one, insofar as perceptions of “giving up” by electing hospice over usual care can be a significant barrier to timely election of the MHB. In a seminal study evaluating the effect of aggressive pain treatment in hospice, it was determined that efficacious pain control with potent opioid analgesics does not influence life expectancy (Portenoy et al., 2006). Thus, it can be concluded that two very important end outcomes of those using the MHB—comfort and life expectancy—are independent measures of effectiveness, and both can be achieved, as demonstrated by these reports.

Caring for a dying spouse can be a highly burdensome and stressful process. An important measure of hospice interdisciplinary team effectiveness is how this support system positively influences survivor well-being. Christakis and Iwashyna (2003) conducted a matched retrospective cohort study involving a population-based sample of almost 200,000 elderly

couples in the United States. Couples who had hospice care were matched with those who did not, and the study recorded the duration of survival for bereaved widows and widowers. Overall, the husbands and wives of decedents who had hospice care outlived those whose spouses died without hospice care (odds ratios of 0.95 and 0.92, respectively, in favor of hospice use). The study's authors asserted that the difference made by hospice in mortality of surviving spouses (especially women) has had as large an impact as other significant modifiable risk factors. They concluded that the interdisciplinary hospice team not only positively affects terminally ill patients' health and well-being, but also that of family members.

### **Lesson Two: The Hospice Benefit Is Economically Sound**

Several studies have attempted to evaluate overall costs of end-of-life care among Medicare beneficiaries who elect for hospice care versus those who use conventional care. Prospective studies with well-matched cohorts are methodologically difficult and costly. Although there is a wide range of purported cost-savings among studies that have been reported, findings suggest lower overall expenditures, along with improved patient- and family-centered outcomes without reduced life expectancy for those who receive hospice care.

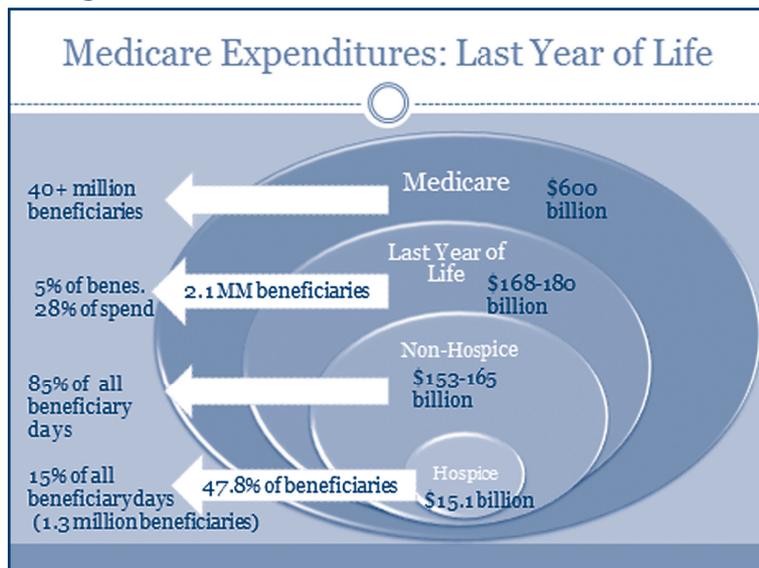
In one of the first attempts to compare MHB versus non-hospice costs of care, Pyenson et al. (2004) performed a combined prospective-retrospective case-control study of 5 percent of the Medicare beneficiary population (1999–2000). They concluded that for the majority of matched cohorts, mean and median Medicare costs were less for patients enrolled in hospice care, and the lower costs were not attributed to shorter lengths of service. The lower cost of hospice care was associated with a longer mean time until death.

In an effort to quantify costs (and potential savings) more accurately, Taylor et al. (2007) employed a method aimed at reducing confounding variables. In a retrospective case-control

study of more than 5,000 Medicare decedents (1993–2003) in various care settings, it was concluded that hospice reduced Medicare program expenditures during the last year of life by the highly statistically significant average

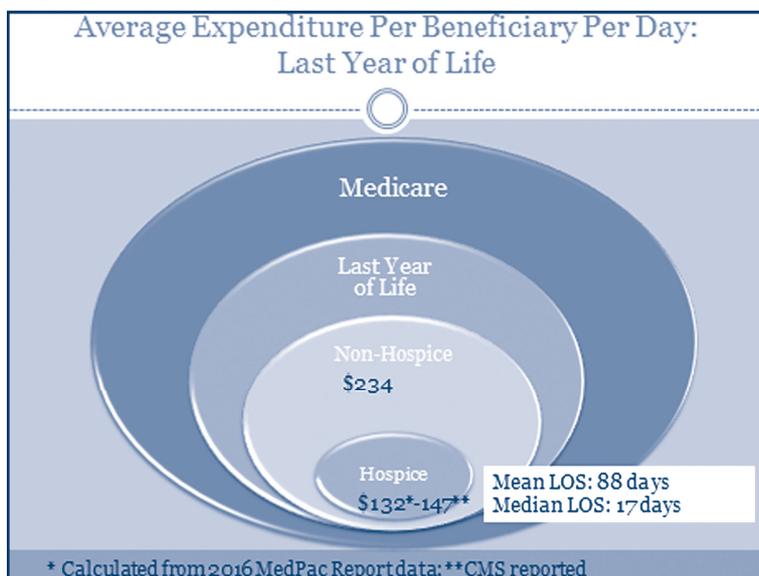
amount of \$2,309 per hospice user (P<0.001). Maximum savings varied between \$3,500 for non-cancer patients (last 50 to 108 days of life) and \$7,000 for cancer patients (last 58 to 103 days of life). These findings have been corroborated by

**Figure 1A. Medicare Expenditures During the Last Year of Life 2014–15**



Source: MedPAC. 2015a. [goo.gl/y5RygE](http://goo.gl/y5RygE).

**Figure 1B. Medicare Average Expenditures Per Day, 2014–2015**



Source: CMS. 2016. [goo.gl/LdSO2W](http://goo.gl/LdSO2W).

studies evaluating different databases in both non-cancer and cancer Medicare beneficiaries at shorter enrollment periods than those previously reported (Kelly et al., 2013; Obermyer et al., 2014). Cost-savings appear to be attributed to reduced hospitalization with fewer intensive care days and invasive procedures.

Because overall satisfaction and quality of hospice care, the dying experience, and family support are reportedly uniformly good, while disruptive transitions of care and hospital deaths are generally undesirable and costly, non-hospice days are a low-value proposition in terms of longevity, quality days, and overall costs of care.

Hospice is under-used and, by inference, every 1 percent increase in hospice days during the last year of life would reduce Medicare expenditures by \$567 million, while improving the beneficiary and family care experience.

**Lesson Three: The Medicare Benefit Has Not Kept Pace with Reality**

The rate of growth of hospice care since 1982, when it became a Medicare Part A carve-out, is unprecedented—from 25,000 patients served per year then, to many more than 1.3 million

## Care Costs During the Last Year of Life

We conducted a macro-economic analysis of care costs during the last year of life, incorporating statistics from all Medicare beneficiaries who died in 2014 (see Figures 1A and 1B on page 62).

From these data, we glean the following:

- Close to 5 percent of all Medicare beneficiaries died.
- Half of all deaths were from cardiac disease and cancer; a breakdown of causes of death from 2013 Medicare data is shown in Table 1, on page 64.
- 30 percent of ages 85 and older Medicare beneficiaries' deaths were attributed to "other causes," including "failure to thrive" and "debility" (National Vital Statistics Report, 2016; National Institutes of Health, 2016).
- 1.3 million (48 percent) Medicare decedents received hospice care for an average of 88 days per beneficiary (15 percent of all decedent days) (Boards of Trustees of the Federal Hospital Insurance and Federal Supplementary Medical Insurance Trust Funds, 2015).
- National Health Expenditures equal \$3.0 trillion (17.5 percent of GDP). Of that \$3.0 trillion: Medicare is 20 percent; Medicaid is 16 percent; hospital expenditures are 33 percent; physician and clinical services are approximately 20 percent; and prescriptions are approximately 10 percent (Congressional Budget Office, 2016).
- Total annual Medicare expenditures in the last year of life are approximately 28 percent of total spending (MedPAC, 2015a).
- 15 percent of all decedent days were spent in hospice, at a total cost of \$15.1 billion (authors' calculation from MedPAC data), or between \$132 and \$147 per day (CMS-reported average cost per day) (MedPAC, 2015b).
- 85 percent of all decedent days were non-hospice days, at a total cost of \$154 billion, an average of \$234 per day, per beneficiary.

The following conclusions can be drawn from these data sources: non-hospice days greatly exceed hospice days during Medicare beneficiaries' last year of life; and during the last year of life, Medicare pays a comparatively high premium for non-hospice days.

per year now (National Hospice and Palliative Care Organization, 2016). Notwithstanding this phenomenal increase in overall hospice use by Medicare beneficiaries, the median length of service has remained both stable and low, averaging between two and three weeks. And more than one out of every three patients that access hospice care dies in less than a week's time, severely limiting its potential benefits.

From a sociological point of view, some perspectives on end-of-life care changed over the past several decades, but other sociocultural attitudes have remained remarkably static. Ap-

preciation for the benefit of the interdisciplinary team approach to terminal care, with an emphasis on comfort and remaining at home when death is imminent, has clearly been demonstrated by the use data. On the other hand, facing mortality (for physicians, family members, and patients) continues to be difficult, playing out in an unwillingness to forego grueling and financially burdensome interventions, with predictably limited—and often reduced—life expectancy and quality days. This psychological schema seems recalcitrant to change. And Medicare, the main payer for those

**Table 1. Cause of Death Among Medicare Beneficiaries: Overall and Medicare Hospice Benefit, 2013**

<b>Medicare Population Mortality (2013)</b>		
<b>Cause of Death</b>	<b>National Statistics</b>	<b>Hospice Statistics</b>
Heart	27%	14%
Nonspecific	23%	<10%
Cancer	17%	36%
Stroke	<10%	<10%
Lung	<10%	12%
Dementia	<10%	15%
Other	15%	14%

Source: *National Vital Statistics Report*. 2016. Deaths: Final Data for 2014. [goo.gl/bwBEcR](http://goo.gl/bwBEcR).

who die from chronic progressive conditions, doesn't help in this process, as its care choices and payment streams remain incredibly difficult to navigate.

An ever-increasing, perturbing, and important determinant of late referral to hospice is prognostic uncertainty. Since the MHB's inception, it has become harder for clinicians to assert with confidence the life expectancy of various patient cohorts, and even more difficult for individuals with most cancers, heart and lung diseases, and dementing conditions (which have seen flatter illness trajectories because of advances in medical, nursing, and supportive care). Certifying a patient as eligible under the MHB's conditions of participation due to "a life expectancy of six months or less if the disease runs its normal course" has become increasingly difficult. In this context, "normal" has greater variability among populations, with consequently lower statistical sensitivity and specificity when applied to individuals who are not demonstrating signs and symptoms of imminent death. In cancer care, an overall survival rate increase ranging from 19 percent to 23 percent has been noted (Siegel, Miller, and Jemal, 2015).

Cardiovascular deaths in the United States peaked in 1990, a mere seven years after implementation of the MHB, but costs of care continue to rise disproportionately with life expectancy (Lloyd-Jones et al., 2010). Nevertheless, cardiovascular deaths make up a large proportion of deaths in the Medicare age group every year. What this means is that we are able to do more and more, at greater and greater cost, with some effect on life expectancy, but it is increasingly difficult to accurately predict a six-month prognosis.

Similarly, but even more pronounced, is predicting life expectancy among the rapidly growing population of Medicare beneficiaries with dementing illnesses. We are now at the mid-point of the epoch in which predictions of a four-fold increase in the prevalence of Alzheimer's disease (from 2.88 million in the population older than age 65 in 1980, to more than 10 million by 2050) are to occur (Evans, 1990).

It is highly likely these trends will continue among the typical chronic progressive conditions that ultimately lead to the demise of most Medicare beneficiaries. The Medicare Conditions of Participation for the hospice benefit have not kept pace with this continuously evolving clinical and epidemiological reality.

#### **Lesson Four: The MHB Is a Model for More Comprehensive and Coordinated Advanced Illness Care**

In the 1990s, when hospice was still getting off the ground, a movement began within academic communities interested in aging and chronic progressive illness to advance a new and emerging medical subspecialty of palliative care. Built around the same basic precepts of hospice, palliative care became the interdisciplinary specialty focused on improving quality of life for persons with serious illness and their families, regardless of prognosis. It was aptly recognized that hospice, under the MHB, was not an acceptable choice for many physicians or their patients, due to the "life expectancy of

six months or less” rule. Even for those with more obviously limited life expectancy, the emotional or cultural impasses of acknowledging imminent mortality created (and continues to create) an insurmountable obstacle to timely hospice admission. Nonetheless, other than bereavement counseling after a loved one has died, the same services and interdisciplinary approach to care are needed with palliative care, and it has proven its merit in non-actively dying patients with advanced illness.

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***Since the MHB’s inception, it has become increasingly difficult for clinicians to assert with confidence the life expectancy of various patient cohorts.***

Beyond the many and nuanced psychological and spiritual issues we grapple with around mortality, far more basic pragmatic issues, such as the requirement of the MHB that those electing that benefit forego “curative” treatment, continue to be unacceptable or confusing to many clinicians and patients. The clinical reality of an ever-lessening discrete line between curative, disease-modifying, and palliative therapies makes a choice between hospice and non-hospice care all the more difficult. Palliative care programs have offered an intermediate solution, but normalization with full integration into healthcare delivery has been slow.

A recent review provides an excellent summary of models of palliative care and the various barriers to more full-scale adoption, access, and implementation (Kelley and Morrison, 2015). It is notable that in comparing hospice (primarily underwritten by the MHB and organized around Medicare Conditions of Participation) and palliative care (largely underwritten by fee-for-service billing, or hospital contracts for services and organized around core precepts, e.g., the National Consensus Project for Quality Palliative Care [2009]), the essential goals of care and the model of

interdisciplinary care teams are virtually identical. Where the differences emerge is in the devilish details of funding, implementation, and integration into healthcare systems. In their review, Kelley and Morrison (2015) conclude by stating, “New models of community-based palliative care are emerging, although data on their cost-effectiveness are not yet available. Gaps in research, workforce deficits, and deficiencies in public and professional knowledge need to be addressed if care for persons with serious illness and their families is to be further improved.”

It is equally true that the creation of the MHB and its application over the years to millions of beneficiaries and their families provide a rich source of experiential and empirical evidence from which to craft more effective but still financially sustainable improvements to advanced illness care.

## **Conclusion**

Legislation and implementation of the MHB was not only innovative, it was revolutionary, given the tens if not hundreds of millions of individuals—beneficiaries themselves, their families, and their larger social circles of friends and associates—touched by the influence of hospice over the past several decades. The explicated lessons learned from an examination of clinical, economic, epidemiologic, and demographic factors draw us to a remarkably simple conclusion. The MHB interdisciplinary and financial at-risk model of care provides a strong foundation from which to build a more inclusive and comprehensive, coordinated, at-risk advanced illness care benefit, consistent with the value proposition posed by the formal construct of the Chronic Care Model.

While earlier and greater use of the current MHB would be beneficial, it would still remain highly de-limiting. It is time for the next iteration of this valuable benefit—one that comports with deep-seated human needs and the past several decades’ advances in medicine. As we

have experienced, these changes will likely lead to increased, not decreased prognostic uncertainty, and even less clear or distinct boundaries differentiating the ability of therapeutics to affect cure, remission, disease modification, and palliation. Regardless of what we call this benefit, or how it evolves within the larger sphere of American healthcare, what must not be lost

along the way is the irreplaceable core virtue of hospice: human dignity. 

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## Authors' Note

Perry Fine serves on the Board of Directors at Magellan Health, Inc. Malene Davis serves on the Board of Directors at the National Partnership for Hospice Innovations.

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# A Prescription for Population-Based Palliative Care Education

By Jason A. Webb  
and David Casarett

Although physicians certainly need to play a role in educating the public on palliative care, more broad public outreach strategies are necessary.

People with chronic, life-threatening illnesses—and their families—face a bewildering array of questions and decisions. These include choices about a surrogate decision-maker and decisions about future treatment, which should all be part of advance-care-planning discussions. People also need to make decisions about goals of care, preferences for treatment, and their desire for information and involvement in decision making. For these choices, and many more, people with serious illnesses need culturally relevant guidance that can help them navigate what is often the most challenging and complex time of their lives.

As the 2014 Institute of Medicine (IOM) *Dying in America* report noted, “Not only do most Americans lack knowledge about end-of-life care choices, which they will at some point so urgently need, but the health community and other leaders have not fully and productively utilized public education and engagement strategies to make that knowledge available in ways that are meaningful and relevant to diverse population groups” (IOM, 2014).

This need for education will only become more important as the population ages. Moreover, healthcare decisions will become more difficult and complex as treatment options proliferate. In the future, patients and their families will need to navigate an increasingly confusing landscape of treatment options, requiring broad and deep improvements in patient education and culture change.

Physicians and other healthcare providers have a role to play in palliative care education. However, more extensive and far-reaching strategies are needed as well. In this article, we suggest that strategies will need to include direct outreach to the public, along with training for healthcare providers that allows them to contribute to population-based palliative care in a meaningful and durable way.

## The Need for Palliative Care Education

Health education in the current American educational systems is poor. The majority of high school graduates lacks basic knowledge of their own anatomy, and many college graduates never

→ **ABSTRACT** The American healthcare system faces a crisis in optimizing care for people with serious, life-threatening illnesses. Many Americans lack basic knowledge of how palliative care services could be helpful, and unfortunately many healthcare providers lack sufficient training to meet the expanding palliative-care needs of our aging population. This article presents a framework for the development of population-based palliative-care education. | **key words:** *palliative care, hospice, serious illness, education, population-based palliative care, public health, end-of-life, advance care planning*

receive foundational training in health science (Paasche-Orlow et al., 2005). That lack of education has created significant barriers to efforts to improve the public's understanding of chronic illness and palliative care, because health literacy is often the major driver in making end-of-life care decisions, more so than even race or religion (Volandes et al., 2008).

The 2014 IOM report examined the current state of palliative care science, and offered a valuable roadmap for efforts to improve the care of seriously ill Americans. Not surprisingly, a recurring theme in that report was the need for improved education (IOM, 2014). One recommendation in particular underscored the need for “culturally appropriate public education and engagement about end-of-life care.” In addition to education of individuals, the report highlighted the need for education of families, communities, and society. This is a call that has been made many times, in other contexts, as engagement and “social medicine” have been proposed as a key part of the medical curriculum (Westerhaus et al., 2015).

Population-based education in palliative care may seem impossibly ambitious. And a broad effort to educate the public about serious illness and end-of-life care will doubtless require tactics, strategies, and tools that haven't yet been employed in the area of palliative care. Such a broad-based effort may be unprecedented in palliative care, but it is not new to other fields.

Numerous efforts in fields as diverse as cardiology and cancer prevention have demonstrated that it's possible to harness the power of public education to promote healthy behaviors and facilitate culture change. For instance, large-scale initiatives have been effective in promoting cardiovascular health behaviors, breast cancer screening, and improved access to immunizations, among other goals (Centers for Disease Control and Prevention, 2016). These initiatives have not been uniformly effective, of course, and future efforts are likely to achieve

varying degrees of success. Nevertheless, in these areas of health promotion and culture change, there have been important gains, and lessons learned, that can help refine future efforts. These sorts of programs, and an organized approach to implementation, can serve as a role model and template for similar efforts in palliative care.

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### ***‘Health education in the current American educational systems is poor.’***

There are notable differences between promoting healthy behaviors in other fields and in palliative care. Education about breast cancer screening, for instance, targets a defined population of people who understand that they are at risk. In contrast, an analogous effort to promote advance care planning requires people to imagine a state in which they are seriously ill and unable to make decisions for themselves. The former requires people to act on a risk they know exists, whereas the latter requires people to imagine a state that they've never considered and would prefer not to contemplate.

Consider an effort to develop public palliative care education initiatives to aid patients in designing advance care plans. For that goal, it might make sense to focus efforts on patients with a new diagnosis of a chronic and potentially life-limiting illness. Those efforts might include developing standards of care that mandate counseling and education regarding advance care planning at time of diagnosis, as well as outreach to their loved ones and caregivers. But these efforts are fundamentally different in aim and scope to, say, promoting breast cancer screening, which offers quantifiable benefits (under the right circumstances) to an individual patient.

Promoting advance planning is challenging because it introduces layers of uncertainty into a message. Although completing an advance directive is commonly promoted as desirable, people may never find themselves in a situation in which others will need to make decisions for

them. Similarly, even if that situation does arise, it may arise in various forms, with wildly varied potential outcomes.

Nevertheless, this and other differences between public palliative care education and other health promotion shouldn't dissuade efforts. Other health promotion activities, such as those related to HIV prevention, have also had to overcome lack of knowledge, misconceptions, and denial. Many of these efforts have been very successful, and public palliative care education efforts may be as well.

The idea of large-scale education culture change in serious illness is not impossible, although it will require a concerted effort, and creative public-private partnerships. Broadly, two parallel and tightly connected approaches are needed, one focused on the public, and one focused on healthcare providers. Specifically, health professionals need to be able to use a shared language with the public so as to dispel fears and taboos surrounding discussing death, dying, and care at the end of life.

#### Healthcare providers' role in public palliative care education

Many health professionals graduating with degrees in nursing, social work, medicine, pharmacy, and psychology have not been trained in core elements of palliative care. Skills in pain and symptom management and communication are not yet a core part of training. Even for fields such as oncology, in which providers will care for patients with palliative care needs, training still is inadequate and uneven (Thomas et al., 2015).

The fundamental building blocks of primary palliative care education have not been integrated into all health professions education in the United States (Quill et al., 2003). A survey published in 2008 assessing U.S. medical students' access to primary palliative care education found that only 30 percent of schools require that their curricula address palliative and end-of-life care training. Furthermore, only

30 percent of schools assessed their graduates' knowledge on this subject.

All healthcare providers should gain core competencies in palliative care, tailored to their needs and scope of practice. Their skills and knowledge need not be equivalent to that which we expect of palliative care specialists, such as physicians, nurse practitioners, and social workers, for whom specialized training and certification programs exist. That is, all providers need skills in "primary palliative care," at a level that allows them to handle the most common palliative care issues and problems (Quill and Abernethy, 2013). One national survey provides a novel way to develop and define the core competencies of palliative care in medical schools and residency programs (Schaefer et al., 2014), identifying five domains, including communication, pain and symptom management, palliative care principles and practice, psychosocial-spiritual-cultural aspects of care, and terminal care and bereavement.

Also, all healthcare providers need specialized training in patient and family education. Particularly in settings where there aren't palliative specialists, other healthcare providers will be patients' and families' primary source of information. Those healthcare providers will also be the voice of palliative care in community outreach efforts. Therefore, all healthcare providers need to be able to speak knowledgeably to the general public about palliative care and end-of-life decisions. This is admittedly a different sort of education than that which health profession training usually provides, but public communication is a necessary skill if we hope to shift behavior and change culture upstream of medical encounters.

#### Educating the Public: Population-Based Education

Although healthcare providers' core competencies—including public communication skills—are essential, education won't be sufficient to change culture. In addition, a broad-based effort of pub-

lic outreach, education, and social marketing is needed. This was a core element of a 1999 World Health Organization recommendation, which emphasized the importance of public education in improving palliative care (World Health Organization, 1990).

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***Two parallel approaches to palliative care education are needed—one focused on the public, the other on healthcare providers.***

To date, there have been no large-scale efforts in the United States to educate the general public or to develop palliative care-focused public health programs. These strategies are routine in other fields of disease prevention and health promotion, but they have not yet been developed and tested in palliative care. However, there are some initial models and approaches that could be used in palliative care.

For instance, the Center to Advance Palliative Care (CAPC) has developed public service messages and programs such as “Get Palliative Care” in an effort to educate patients with serious illnesses regarding their care options (CAPC, 2015). These and other products offer basic education about palliative care, and how it can benefit patients and families. However, these preliminary efforts haven’t been widely disseminated. More importantly, their impact has not been tested rigorously in a way that would guide future tailoring of messages and delivery strategies. Future studies examining the impact of advance-care-planning outreach to seriously ill patients would be helpful to determine what types of outreach are most effective. Pilot studies may give deeper insight into how to best disseminate the message to younger and healthier adults, because most people lack the basic understanding of the role palliative care might play in their life span.

Given the absence of broad-based efforts, it is not surprising that the public has begun to fill

the gap in education. A variety of grassroots efforts have arisen, including the development of social networking programs such as the Death Café movement, which brings people together for informal discussions about death. Some of these efforts have been carefully orchestrated and organized, but others have been more organic. One art installation in New Orleans allowed passersby to write in a description of what they wanted to do before they die. That project soon grew into an international movement, as the same installation was replicated in cities around the world (Chang, 2016).

Such grassroots efforts are heartening, and indicate that the public has an appetite for palliative care conversations and information. But these efforts aren’t enough. Next, the public health arms of the U.S. government, such as the Department of Health and Human Services, the Centers for Disease Control and Prevention, and the Surgeon General’s office need palliative care specialists’ guidance and expertise to develop large-scale efforts.

***A prescription for population-based palliative care education***

A comprehensive, broad-based effort to educate the public about palliative and end-of-life care is ambitious, but not impossible. We have examples to draw on from a wide range of other fields, growing enthusiasm that is evident from grassroots efforts, and a small but growing workforce of palliative care specialists. A public education initiative has the potential to catalyze existing enthusiasm and offers a unique opportunity to normalize palliative care and end-of-life decisions in a way that hasn’t been possible in the past. This is an optimal time to add public education to existing strategies to improve the care of people with chronic, serious illness.

Palliative care education has to be patient- and family-centered, and at least initially focused on our most vulnerable older and chronically ill population. But also we need to plan for large-scale public education that will

engage healthy populations considering their end-of-life wishes and those of their families. Many adults are ill-prepared to face a healthcare crisis, and are unaware of the need for advance care planning. They may be even less prepared to support a sick family member or loved one. Our ultimate goal should be to engage healthy adults and their family members to express care goals when navigating an often nebulous and complex healthcare system.

If the imperative for public education is clear, it is less obvious what strategies are likely to be most successful. Nor is it obvious what messages are most effective, or how those messages should be delivered. It is not even known how to define success in a public health intervention, or how to measure its impact.

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***‘Research is needed to understand how best to deliver population-based palliative care education.’***

There is an urgent need for research to develop an evidence base for population-based palliative care education. Just as academic medical systems are ideally suited to promote population-based healthcare, so, too, are they well-prepared to advance the science of population-based palliative care education (Gourevitch, 2014). Research to advance the field should develop messages that are most likely to resonate with the general public, giving special attention to developing messages that are most appropriate for specific audiences (e.g., patients with chronic illness, people who are healthy; family members of people nearing the end of life).

Research also should define ways in which messages and content should be tailored to demographic characteristics, including race, ethnicity, and cultural background. Studies also are needed to clearly define the outcomes that should be measured, a question that has plagued

other population health initiatives (Aguilar-Gaxiola et al., 2014).

Finally, research is needed to understand how best to deliver population-based palliative care education. Given the scope of the need, and the urgency of education for an aging population, traditional methods such as public service announcements are likely inadequate. In addition, a population-based palliative care education effort offers exciting opportunities to explore innovative approaches to broad-based behavior change (Casarett and Teno, 2016). Considering the near ubiquitous public interest in mobile technology and social media, these tools may be the portal of entry to greater population-based education.

**Conclusion**

This strategy will require a fundamental re-evaluation of the way palliative care is defined and delivered. We can no longer afford to think of palliative care as a specialty to which relatively small numbers of patients are referred, any more than we can maintain the belief that cardiology is a largely procedural specialty. Just as cardiology and other fields have transformed their image and vision by embracing a public health mission (Knapper et al., 2015), palliative care needs to expand its mission to include changing the culture of serious illness and end-of-life care. 

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# The Changing Landscape of Palliative Care

By Diane E. Meier  
and Brynn Bowman

A brief history of palliative care, plus new methods under development by health systems, insurers, and population health managers to embed such care where it is most needed.

**A**n arsenal of new technologies and treatments now allow us to prevent, cure, and live longer with disease. While medical science has relentlessly advanced treatments for the seriously ill, the science of ensuring dignity and quality of life for these patients has lagged behind. Palliative care, which emerged as a specialty in order to address the suffering of patients who live with serious illness, is specialized medical care focused on providing patients with relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and his or her family. Provided by an interdisciplinary team, palliative care is appropriate at any age, and at any stage in a serious illness, and can be provided concurrently with curative treatment.

The principles of palliative care are inherent in the structure of the interdisciplinary team. Per field guidelines, the core palliative care team consists of a physician, nurse, social worker, and chaplain (National Consensus Project, 2004–2016). Working together, this team addresses the medical, social, cultural, and spiritual needs

that arise when patients and their families and/or their caregivers are faced with a diagnosis of serious illness.

## The Hospice Movement

Palliative care has its roots in a hospice movement that began centuries ago. The religious orders of the Middle Ages originally opened their doors to provide “hospice” (rest and shelter) for weary travelers. These institutions evolved into havens for sick, elderly, or disabled people who had no other place to turn (Meier, Isaacs, and Hughes, 2010). Centuries later, Dame Cicely Saunders volunteered her time at a modern descendant of the religious hospice—a Catholic home for the dying in London. Inspired by the work of nuns who opened their doors to patients when traditional medicine had nothing more to offer, in July 1967 Dr. Saunders founded St. Christopher’s, the first modern hospice, in a suburb of London (St. Christopher’s, 2016). With Saunders as a mentor, Florence Wald started the first American hospice in 1974 in Connecticut, and created an extensive hospice nursing cur-

**→ABSTRACT** As the number of Americans living with serious illness grows, how will our fragmented, top-heavy healthcare system respond? How can we ensure high-quality care for our most vulnerable patients? The evolution of palliative care provides insight into efficient, effective models of care for seriously ill patients in their communities, and the system redesign and workforce repositioning that will be necessary to respond to our seriously ill patients’ needs and preferences at a national scale. | **key words:** *palliative care, serious illness, hospice, value-based payment*

ricula at the Yale School of Nursing, stating, “Hospice care is the epitome of good nursing care” (Dahlin, Coyne, and Ferrell, 2016).

These hospice pioneers held the conviction that incurably ill patients deserved to live out their days in comfort and with dignity, and that the role of the clinician did not end when disease treatment stopped being effective. The implications of this perspective ran counter to a mainstream “culture of cure,” in which dying patients were largely invisible.

When Dr. Elizabeth Kübler-Ross in 1966 began to interview dying patients for her influential book *On Death and Dying*, her colleagues dubbed her “ghoulish” (American RadioWorks, 2004). To focus on the experience of dying, they feared, could frighten patients and even undermine their trust in the medical community.

As a grassroots movement on the fringes of the medical community, early hospice workers were tasked both with changing hearts and minds, and with building a science of comfort care.

In 1982, these efforts were recognized when hospice care was added as a Medicare benefit for patients near the end of life. In subsequent years, most private insurers followed suit; since then the hospice field has grown exponentially.

### **Palliative Care’s Early Days**

To be eligible for the Medicare Hospice Benefit, a patient must be within six months of the end of life and must agree to forego curative treatment. These criteria exclude those patients who are pursuing disease treatment but have need for supportive care, or who have serious illness with a prognosis longer than six months. In recognition of these gaps, the first palliative care programs were launched in the late 1980s to provide consults for seriously ill patients in the hospital who were ineligible for hospice or who chose not to receive it.

Palliative care eligibility is based solely on need, and is as appropriate for a child undergoing curative leukemia treatment as it is for an

elderly patient at the end of life. Unfortunately, widespread confusion about the difference between palliative care and hospice persists even today. The unfortunate side effect is that some patients choose to forego much-needed services because they equate palliative care with end-of-life hospice care. Though public awareness is slowly growing, education about the benefits of palliative care to patients and caregivers is as critical today as it was in the days of the first palliative care programs.

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***Palliative care is appropriate at any age, and at any stage in a serious illness, and can be provided concurrently with other treatment.***

Another early impediment to the growth of palliative care was that its services were fundamentally mismatched to the dominant fee-for-service reimbursement structure in place to fund clinical services. With its focus on patient-centered care for patients with complex needs, palliative care is time-consuming. The cost of clinicians’ time cannot be offset by the revenue-generating procedures (i.e., surgeries, treatments, and other interventions) that may fund other specialty services such as oncology or cardiology. Without data on the patient outcomes and cost implications of palliative care, early programs were dependent for resources on administrators who believed such care was the right thing to do.

Despite such challenges, palliative care programs proliferated in the late 1990s and early 2000s. Nursing became the first clinical discipline in 1998 to offer certification in palliative care. In 2006, the American Board of Medical Specialties followed suit by establishing the subspecialty of Hospice and Palliative Medicine (board certification in the field is now available to eleven parent specialties), and specialty certifications were subsequently launched in social work and chaplaincy. In 2004, the National

Consensus Project published its *Clinical Practice Guidelines for Quality Palliative Care*, which articulated the clinical and structural elements of quality palliative care programs (National Consensus Project, 2016).

### The tipping point

The rapid growth of palliative care reached a tipping point because of three occurrences, the first being the establishment of a business case for palliative care programs. A 2008 *JAMA Internal Medicine* study found that palliative care consultations resulted in nearly \$5,000 in hospital savings per admission; subsequent studies reported similar outcomes (Morrison et al., 2008).

In addition to being the right thing to do for seriously ill patients, palliative care had been demonstrated to positively impact hospitals' bottom lines. Meanwhile, the *New England Journal of Medicine* published a study in which patients with lung cancer who received palliative care reported better quality of life, had lower rates of depression, and lived longer than their peers who received usual care (Temel et al., 2010). This paper, and others, built the quality case for palliative care.

Then, in 2011, The Joint Commission (2016) announced the launch of its Advanced Certification Program for Palliative Care for hospitals that provide palliative care services in accordance with quality standards. With the clinical and business cases clearly articulated, and the structural elements for quality palliative care codified, the number of palliative care programs across the United States rose rapidly. Between 2000 and 2013, the percentage of U.S. hospitals with fifty or more beds that had palliative care programs jumped from 24.5 percent to 72.3 percent (Dumanovsky et al., 2015).

### Palliative Care Today

Today, more than 90 percent of large (more than 300 beds) U.S. hospitals and 66 percent of all hospitals nationwide report having palliative

care services. Included in this number are the top twenty National Institutes of Health–funded hospitals, and 97 percent of the Council of Teaching Hospitals member organizations. Access to quality palliative care services is a Commission on Cancer accreditation standard (Commission on Cancer, 2015). Hospital palliative care is now the norm rather than the exception, and many teams have turned their focus to ensuring the timeliness of palliative care consults. While the positive impact on quality of life for patients receiving early palliative care is clear, research has also shown that earlier palliative consults also reduce costs. Cost-savings for a hospital episode of care for patients with advanced cancer, for example, increase from 14 percent to 24 percent if a palliative care team sees a patient two days into an admission, versus six days (May et al., 2015).

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## ***The care that roughly 1,600 hospital palliative care teams provide represents a small fraction of unmet need.***

The rapid proliferation of hospital palliative care across the past fifteen years reflects the realization that seriously ill patients need more than what our healthcare system is structured to deliver. Still, the care that roughly 1,600 hospital palliative care teams are able to provide represents a small fraction of unmet need. While palliative care needs may be urgent and acute during a patient's hospital stay, what happens when he or she is discharged and sent back home? For the millions of Americans living with serious illnesses, the majority of care is received in a clinic, at a nursing home, in the patient's own home, or in other community settings.

Today, very few communities have access to non-hospital palliative care in any form other than hospice. This means that only patients who are in crisis (hospitalized) or dying (in hospice) receive palliative care. As recognition grows that the most vulnerable and costly patients do better

when cared for in their own homes and communities, new models of community palliative care are emerging.

#### Growth of palliative care, at home and in community

Community programs provide an excellent opportunity for early and consistent involvement of palliative care for patients with high-burden illnesses or unpredictable disease trajectories.

Many of the nation's sickest and most vulnerable patients live at home, are unable to travel to appointments at a clinic, and are not enrolled in hospice. While many early home palliative care programs began as offshoots of hospital consulting services, a growing number of community-based organizations have begun to provide home palliative care as well. One common model is a hospice agency that establishes a separate business line in order to provide patients in its region with palliative care before they are eligible for the Medicare Hospice Benefit. Home health agencies may establish a similar structure; group practices may launch a home palliative care program to provide supportive services for their high-need patients; and health systems are turning to home palliative care delivery as a way to provide continuity of care after hospital discharge and to prevent future crises and readmissions by addressing patients' complex needs at home.

One such health system is Sharp HealthCare in Southern California, an Accountable Care Organization (ACO) in the Pioneer ACO program, whose Transitions palliative care program provides home palliative care that is titrated to patients' needs. Patients in the "acute" phase receive several visits per week from the program's registered nurses and social workers, as well as from spiritual care providers, upon request. Once symptoms are controlled and the patient's goals have been documented, patients move into the "maintenance" phase in which in-person visits decrease, but close contact is kept via telephonic case management.

The program has demonstrated high patient satisfaction and significantly reduced costs, particularly at the end of life. Compared to usual care, total monthly care for Transitions patients costs between \$2,690 less (for patients with dementia) to \$4,258 less (for patients with cancer) (Cassel et al., 2016). Other studies have shown that patients who receive palliative care at home are more likely to die at home, which is the preference for a majority of U.S. patients (Brumley et al., 2007).

#### Palliative care in long-term-care settings

On any given day in 2012, more than 2 million Americans were living in nursing homes or residential care communities such as assisted living facilities. More than 45 percent had a diagnosis of Alzheimer's disease or other dementias, and more than 40 percent suffered from depression (Harris-Kojetin et al., 2013). While there is no care setting in which the need for palliative care is more clear, as of today, non-hospice palliative care services are rare in long-term-care residences. Among those that provide palliative care, some long-term-care facilities embed specialty-trained staff at their locations and offer services in house. Others partner with local palliative care providers (from a hospice, a hospital, or a home-visit palliative care consult service) that provide consultations at the long-term-care facility.

A 2016 study of forty-six nursing homes in North Carolina and Rhode Island showed that patients who received palliative care consultations in the nursing home had markedly fewer emergency department visits and hospitalizations near the end of life than did their non-palliative-care counterparts. Among patients who received palliative care within 180 days of death, only 7 percent were hospitalized in the last week of life, compared with 23 percent of patients who did not receive palliative care (and the earlier that palliative care consultation began, the fewer hospitalizations occurred) (Miller et al., 2016). Total Medicare expenditures also decreased for pa-

tients who received palliative care. In a population where transitions to and from the hospital are particularly distressing and burdensome for patients and their families, lead to poor health outcomes, and incur high costs, palliative care is an urgently needed intervention.

#### Palliative care in the clinic

Models for palliative care delivery in an office setting include embedding palliative care-trained staff and services in specialty clinics or co-locating palliative care services with another practice, both of which allow for convenient referrals to the service and easy scheduling so patients can minimize visits. Like palliative care that is delivered in long-term-care settings and in patients' homes, clinic-based palliative care leads to improved outcomes for patients. The impact of palliative care delivery in an office setting has been most thoroughly researched for patients with cancer; multiple studies have shown increased use of hospice services, de-

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### ***'Palliative care is the rare win-win for risk-bearing organizations.'***

creased hospital use, and decreased costs of care compared with patients who do not receive palliative care. For example, through a 2012–2015 CMS Innovation Award, the University of Virginia collected outcomes for patients who received consultation in a palliative care clinic through the Comprehensive Assessment with Rapid Evaluation and Treatment (CARE Track) program, concurrent with disease treatment at the University's cancer center. Clinicians in the CARE Track program work in close partnership with a patient's oncology team and provide symptom management and care planning for patients who have incurable malignancies. CARE Track patients were more than three times more likely to receive hospice care before death than were control patients, and incurred lower costs during the last three months of life due to re-

duced numbers of hospitalizations (Blackhall et al., 2016).

#### The Future of Palliative Care

When in 2001 the Institute of Medicine released its groundbreaking report *Crossing the Quality Chasm*, it shined a spotlight on glaring gaps in care and care quality in the U.S. healthcare system. Numbers two and three of the report's recommendations—"Care is customized according to patient needs and values," and "The patient is the source of control"—lie at the heart of palliative care principles and practice. Palliative care evolved to address the gaps of a fragmented, hyper-specialized system for the patients whose needs are both chronic and complex. As such, palliative care models of practice and clinical expertise provide a playbook for the evolution of the healthcare system writ large.

Since the passing of the Affordable Care Act, health systems across the country have material motivation to reduce unnecessary hospitalizations, improve care quality while maintaining or reducing costs, and ensure patient and family satisfaction. Increasingly, insurers, ACOs, Patient-Centered Medical Homes, and other population health management or risk-bearing entities are turning to palliative care for evidence-based models of care that address the needs of seriously ill patients. Today, palliative care growth is limited by the lack of trained specialists, and inadequate funding (under the fee-for-service model) for community palliative care services.

#### Training the Workforce

It is estimated that more than 10,000 additional palliative care physicians would be needed to meet the demands of the current U.S. population of seriously ill patients—and the number of people living with serious illness grows daily (Lupu, 2010). This shortage in specialty-trained clinicians is equally acute in the disciplines of nursing, social work, and chaplaincy. If the healthcare system is to realize the value of

palliative care in terms of care quality and reduction of unnecessary hospitalizations and costs, clinicians working outside the specialty must receive training in core palliative care clinical skills.

A number of mid-career training options for non-palliative care specialists from all disciplines exist in online and in-person formats, and healthcare providers from all settings have begun to train clinicians to manage pain and symptoms, discuss care plans with seriously ill patients, and ensure well-coordinated transitions (Center to Advance Palliative Care, 2016; American Association of Colleges of Nursing, 2016; VitalTalk, 2016). Such training is particularly needed in organizations or locations where specialty palliative care is not available.

### **Paying for Palliative Care**

Alternative payment models now make up nearly a third of Medicare payments and represent an enormous opportunity to expand palliative care. Given its track record of improving patient outcomes (quality) while reducing use (costs), palliative care is the rare win-win for risk-bearing organizations. Increasingly, payment for both hospital and community palliative care services are being negotiated at the patient or population level rather than being billed on a fee-for-service basis.

The Centers for Medicare & Medicaid Services (CMS) and private insurers have begun to fund pilot programs that address the palliative care needs of the highest-risk, highest-cost patients. One example is the CMS Independence at Home Demonstration, which provides in-home primary and palliative care services to Medicare patients who have multiple chronic conditions, a hospitalization within the previous year, and two or more functional limitations. This is a group most in need of, and likely to benefit from, palliative care principles and practices. Launched in 2013, the program is designed to provide “in-home visits tailored to an individual patient’s needs and preferences” (CMS, 2016).

Second-year results show that seven of the fourteen participating provider organizations met quality standards for the program while reducing care costs (CMS, 2016). Another example is Aetna’s Compassionate Care program, which provides specialized training on the needs of seriously ill patients for care managers and expanded hospice benefits for Medicare Advantage members enrolled in the program. Compassionate Care has shown increased patient and family satisfaction, decreased ICU days, and significant reductions in total cost of care (Krakauer, Agostini, and Krakauer, 2014).

Both Independence At Home and Compassionate Care are designed to address the palliative care needs of the seriously ill population—consistent management of symptoms to avoid health crises, coordination of care across settings and providers, support for family caregivers, and conversations that lead to goal-concordant care. As the healthcare system struggles to meet the needs of an aging population and adapt to alternative payment models, these programs serve as a template for the future.

### **Responding to the Need**

The remarkably fast growth in palliative care across the past twenty years is indicative of changing attitudes on the part of healthcare administrators and clinicians, and of care that resonates with patients and families.

The principles and practices that underlie palliative care—for example, spending extra time with a patient to talk about what to expect when the disease worsens—are not cutting-edge. They are as old as human caring. What *is* cutting-edge are the methods being developed by forward-thinking health systems, insurers, and population health managers to embed palliative care in the places where and at the times when patients need them most. 

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# Hope for Persons with Dementia: Why Comfort Matters

By Tena Alonzo

Comfort care can help avoid the most difficult behaviors associated with Alzheimer's disease and other dementias.

For more than 100 years, people with dementia have been cared for using a traditional care model, sometimes with little consideration of whether or not this model is effective. As society gains a greater understanding of what it means to experience dementia, there are more opportunities to redefine how best to support people with dementia. Creating a comfort or palliative care model is giving new hope to families and the promise of less distress for persons living with dementia.

More than 9 million people live in more than 45,000 long-term-care organizations across the United States (Centers for Disease Control and Prevention, 2014). As of 2010, more than 42 percent of individuals living in long-term-care organizations were diagnosed with dementia, making dementia the second most common disease experienced by persons living in these settings (Caffrey et al., 2012). As the number of people with cognitive impairment has increased, so has the number of dementia units in the long-term-care industry. Typically, the care and service offered in long-term-care organizations has not been tailored to meet the needs of people who

have trouble thinking. Sadly, palliative care, or comfort-focused dementia care, may not be available when it is needed most.

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***One way to ensure receiving comfort or palliative care is to implement it well in advance of end of life.***

Realizing the role comfort plays in the lives of people with dementia and implementing a comfort-focused program is not without its challenges. Creating change in long-term-care organizations requires time, orchestrated effort on the part of staff, and sometimes a reallocation of financial resources. Although creating access to comfort for people with dementia requires changes in staff practice and organizational adaptations, there is no evidence that these changes increase costs (Alonzo et al., 2016).

## **Improving Quality of Life at Beatitudes Campus**

Nearly two decades ago, Beatitudes Campus, an older adult community in Phoenix, Arizona,

→ **ABSTRACT** Access to palliative care for persons with dementia can improve quality of life and quality of care. Getting to know the person with dementia fully, and developing care strategies focusing on her or his comfort can make a huge difference. While comfort is unique to each person, there are considerations that can help nursing homes and assisted living communities adopt and embed comfort through staff practice and individualized organizational routines. Creating awareness regarding the positive impact comfort has on persons with dementia is the first step in making it available everywhere. | **key words:** *dementia, comfort care, palliative care, Beatitudes Campus*

## The Road to Comfort—Roger's Story

Roger was diagnosed with Alzheimer's disease five years ago, and two weeks ago moved from his daughter's home to a dementia neighborhood. He has been widowed for ten years and has two adult children. Roger, who is 77 years old, has also been diagnosed with osteoarthritis and degenerative joint disease. His son and daughter report that six years ago he had a total right knee replacement, and was planning to have the same surgery on his left knee when diagnosed with Alzheimer's disease. As a result of that diagnosis, Roger opted not to have surgery on his left knee.

Roger receives acetaminophen twice a day at 8 a.m. and 8 p.m., and he has an as-needed order for a low dose of anti-anxiety medication when he refuses to bathe.

The staff reports that Roger is rejecting any effort to help him bathe, yet is unable to bathe himself. When sharing this information with Roger's family, his daughter tells the staff he has refused to bathe at home, too. Roger's children are confused about why he is unwilling to let the staff help him bathe and they are embarrassed that he has cursed at the staff and called them names. They let the staff know their dad has always been a kind and gentle person and his actions are completely out of character for him.

The healthcare team met with Roger's son and daughter to make sure they had all the facts. During the discussion, the team members learned that Roger has been rubbing his left knee for long periods of time while living with his daughter. His son voiced concern that his dad is not as mobile as he used to be and he wondered if this was related to the progression of dementia. Roger had not complained of pain and his children figured that he rubbed his knee out of boredom or habit.

The healthcare team asked Roger's family about his bathing preferences. They learned that he used to shower every evening before bed. The certified nursing assistant who was responsible for helping Roger bathe reported that his shower has been offered between 7 a.m. and 8 a.m. twice a week.

The team also asked what Roger liked to do when relaxing, and whether anything comforted him when he was in pain. Roger's son said that before his first knee surgery his dad would sit in his recliner and listen to Johnny Cash or Elvis Presley. His son also said that occasionally his dad would go for a brief walk to ease discomfort.

With this additional information, the neighborhood team was ready to create a plan to help Roger with the discomfort associated with bathing (see Table 1 on page 83 for the new plan).

As the neighborhood team followed Roger's Road Map to Comfort, his actions of discomfort diminished greatly, and Roger enjoyed bathing once a week. The team learned that Roger was experiencing significant pain in his left knee but, after receiving additional pain medications, stopped rubbing his knee. They also discovered that he enjoyed Johnny Cash music better than anything else, so they would play his favorite songs prior to attempts to get him to bathe. Roger's children were told of the change in Roger's comfort and were relieved to know their dad was once again the kind and gentle man they had always known.

made a critical decision to improve the quality of life and quality of care for people living with dementia. This decision grew out of a realization that persons with dementia often encountered challenges beyond what they could tolerate and, as a result, frequently experienced avoidable negative outcomes.

Opened in 1964, Beatitudes Campus has served the Phoenix area for more than fifty years and is home to 700 people ranging in age from 58 to 104. Sponsored by the Church of the Beatitudes United Church of Christ, the campus is a faith-based, nonprofit organization driven by innovation.

**Table 1. Roger's Road Map to Comfort**

How did Roger tell the staff about his discomfort during bathing?	What did Roger's actions likely mean?	What can the staff do to reduce Roger's pain, enhance his comfort, and decrease his actions of discomfort?
When entering the bathroom, Roger yells at the staff to go away and leave him alone.	Bathing causes Roger physical pain. The staff believe that when he rubs his knee, this is a sign of physical pain.	Use a pain observation tool, such as PAINAD, several times a day to assess Roger's level of pain.
If the staff persists, he curses and calls the staff names.	This routine of bathing in the morning doesn't feel right to him.	Report outcome of the pain assessment to the medical provider and adjust pain medication.
If the staff attempts to help him remove his clothes, he swings his fist at them.		Offer Roger assistance with bathing in the evening since this is his lifelong preference.
		Prior to offering Roger assistance and during the bathing experience, play Johnny Cash or Elvis Presley music for him.

At first, leaders at Beatitudes Campus were uncertain how to improve quality of life and quality of care for people with dementia. Inspired by the early pioneers of the person-centered care movement, the campus identified access to comfort and personhood as the mechanism for improvement (Kitwood, 1998). Campus leaders believed that access to comfort should be an everyday occurrence, and not one only

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***Staff discovered that Roger enjoyed Johnny Cash music beyond anything else, so they played his favorite songs before persuading him to bathe.***

associated with dying. In essence, the comfort that people with dementia deserve should fall in line with their lifetime of experiences and patterns. If campus management was willing to change how staff practice, and the systems that govern how care and service were delivered, residents would have access to such comfort care (March and McCormack, 2009).

Once Beatitudes Campus began to focus on comfort for people with dementia, positive changes happened quickly. Staff noticed that when people with dementia were comfortable they did not call out for help frequently, and when staff helped them go to bed, individual fall rates decreased. Staff and family members acknowledged that if the person with dementia was comfortable, many challenges associated with dementia could be minimized or stopped. Actions of discomfort such as rejecting care, wandering, and repetitive calling out stopped when comfort became a care goal.

### **Defining and Applying Principles of Comfort Care**

There are several definitions of comfort or palliative care and how it applies to people who have cognitive impairment. According to the National Hospice and Palliative Care Organization (NHPCO), "Palliative care is patient- and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intel-

lectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information and choice” (NHPCO, 2016).

While most medical providers acknowledge the benefit of comfort or palliative care, particularly at the end of life, they often question when to initiate such care. This ambiguity comes from the difficulty in predicting with certainty when death is approaching for people who have dementia, which means people with dementia and their families can miss out on the benefits of hospice (Birch and Draper, 2008).

One way to ensure that people with dementia will receive comfort or palliative care is to implement it well in advance of end of life. Generally, people spend their lives doing what is most comfortable, and dementia does not diminish the importance of this tendency, but the disease makes it more difficult for people to comfort themselves. Beatitudes Campus staff created a palliative care program that addressed individualized comfort for each person with dementia. Ultimately, this comfort model focused on the following opportunities:

- to sleep when tired;
- to eat what is appetizing, whenever hungry;
- to accept assistance with personal care that is individualized and makes sense to the person;
- to be engaged in meaningful ways, considering unique interests and lifelong pursuits; and
- to live in a community or environment that genuinely seeks to promote personal autonomy through balancing sensory stimulating and calming events.

People with dementia often experience changes in sleep patterns. Frequently these changes result in periods of sleep during the day and more time spent awake at night. Much of the time, attempting to regulate the person’s sleep-wake cycle to sleep at night and be awake during the day can cause discomfort and distress. Adapting the organizational routine to support the person’s sleep cycle ensures comfort and can reduce the likelihood of any distress related to fatigue. Once the staff adapted

their routines to fit what was most comfortable for persons with dementia, work became easier and more enjoyable. It was interesting to note that additional staffing was not required and for some, roles decreased as each person with dementia achieved her or his optimal comfort.

Sleeping according to each person’s routine promotes opportunities to eat when the person is awake and hungry. Making foods available that appeal to the person with dementia is essential to overall comfort and well-being. More than a decade ago, the American Academy of Nutrition and Dietetics urged a liberalization of diets for people living in institutional settings (American Dietetic Association, 2005). For many people with dementia, eating the foods they enjoy is the most comforting experience they have at any given time. These foods often are not complex, examples include peanut butter and jelly sandwiches, ice cream, or chocolate pudding cups. Over time, the campus replaced the nutritional supplements offered to persons with dementia with simple snacks, which generated an annual cost savings of nearly \$30,000.

People with dementia have spent decades figuring out how to best take care of themselves and are experts on what works for them and what brings them comfort. They bathe or brush their teeth in certain ways. Approaching dressing, grooming, and bathing on each person’s terms will reduce the likelihood of them rejecting care (Smith and Buckwalter, 2005).

Scheduled group events like Bingo or arts and crafts do not necessarily constitute meaningful engagement, but instead staff should make an effort to know the person and how they enjoy spending her or his time. Any person with dementia can become bored, although boredom may be difficult for caregivers to identify because the person with dementia may not be able to communicate her or his boredom, or initiate doing what she or he enjoys. Most of the time, the engagement that brings the most joy to people with dementia is highly individualized

and involves a one-on-one approach (Cohen-Mansfield et al., 2010).

Many places where people with dementia live have a lot happening all at once. It is understandable that if many people live under the same roof there will be noise and commotion. However, people with dementia struggle to make sense of the environment, especially if it is chaotic and noisy, and can become overwhelmed by too much stimulation. They may have reached a point of overload when they look for the exit, ask to go home, or call out. Comfortable environments for people with dementia balance what is happening in the environment to avoid overwhelming them (Teresi, Holmes, and Ory, 2000).

## Conclusion

Access to palliative care for persons with dementia can improve quality of life and quality

of care. Getting to know the person with dementia fully and developing care strategies that focus on her or his comfort can make all the difference. While comfort is unique to each person, there are considerations that can help nursing homes and assisted living communities adopt and embed comfort through staff practice and individualizing organizational routines. Currently, multiple nursing home and assisted living organizations across the country are replicating the work initiated at Beatitudes Campus, with similar positive outcomes. Continuing to enhance awareness regarding the positive impact comfort has on persons with dementia is the first step in making it available everywhere. 

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# Next-Generation Quality Measurement to Support Improvement in Advanced Illness and End-of-Life Care

By Helen Burstin  
and Karen Johnson

Assessing and rewarding care based on value should encourage more virtual or home-based care, and increase the perceived value of palliative care.

The overarching purpose of measuring healthcare performance is to drive improvements in care. The shift to paying for value over volume has driven a focus on measuring outcomes, including patient-reported health outcomes, patient and family experience, values and preferences, and shared decision-making. This seismic shift in performance measurement is affecting all aspects of care, including palliative and end-of-life care. A focus on value logically leads to a discussion of longitudinal assessment of cost and outcomes.

Efforts to measure and improve the quality of care for patients near the end of life are not new. Harkening back to the “Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments” (SUPPORT) in the early 1990s, we learned that physicians often were mistaken about their patients’ preferences regarding resuscitation (Teno et al., 1994), and that making improvements in this area would not be easy (Teno et al., 1995).

With its 1997 publication of *Approaching Death: Improving Care at the End of Life* (Institute of Medicine Committee on Care at the End of Life, 1997), the Institute of Medicine helped to define high-quality end-of-life care and offered extensive recommendations on how that care could be improved. Early measurement efforts, including the Assessing Care of Vulnerable Elders project, worked to identify valid measures of end-of-life care, although many were limited by the availability of empirical evidence (Wenger and Rosenfeld, 2001).

However, the U.S. healthcare system still does not always effectively measure whether patients and families are receiving high-value palliative and end-of-life care. This is poised to change, as the aging of the U.S. population and the rapid rise in the number of Americans with multiple chronic conditions has led to a renewed focus on measuring performance for those facing critical decisions about value-based care at end of life. To significantly improve the quality of

**→ABSTRACT** The shift in healthcare policy to paying for value will drive how we measure the quality of palliative and end-of-life care. This article identifies some of the challenges of measuring the quality of palliative and end-of-life care, and discusses public–private partnerships and their progress in creating and developing consensus around effective quality measurement. It describes the attributes of the next generation of measures for palliative and end-of-life care, and their use as a tool in risk-based, alternative payment models to promote improved care. | **key words:** *performance measurement, value-based care, consensus, palliative care, end-of-life care, quality improvement, quality measurement*

care individuals receive at the end of life, it is imperative that consensus-based efforts help identify measurement gaps, rapidly develop needed performance measures, implement promising measures into payment programs and public reporting, and share best practices for care and improvement.

### **Garnering Consensus for Measuring End-of-Life Care Quality**

Developing and implementing measures that are the most likely to drive improvements in care is complex, resource-intensive, and often controversial. Measure developers and implementers must decide which entities in the healthcare system should be held accountable for care quality, which data sources to tap for reliable and valid measurement, and how to construct measures that then can be used to make fair comparisons between providers of care. For palliative and end-of-life care measurement, the process may be even more complicated. Many of the typically measured outcomes of care, such as survival or improved functional status, may not be appropriate and the optimal time frames for measurement may not be apparent.

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### ***Efforts to measure and improve the quality of care for patients near the end of life are not new.***

Yet given the crucial role of measurement in improving palliative and end-of-life care, as well as the increased use of performance measures in public and private accountability applications, it is vital that stakeholders agree on the most important measures that can drive improvement. Although an assortment of measures is necessary to adequately assess different aspects of the healthcare system, stakeholders should agree upon and promote using performance measures that minimize the administrative burden on providers of collecting and reporting data. Such measures also can reduce confusion among stakeholders, who may have to interpret seem-

ingly contradictory results when using and reporting on similar, but not identical, measures.

In 2013, the American Academy of Hospice and Palliative Medicine (AAHPM) and the Hospice & Palliative Nurses Association (HPNA), in collaboration with other stakeholders, initiated a consensus project called Measuring What Matters (AAHPM and HPNA, 2016a). The goal of this effort was to recommend a small set of valid, clinically relevant performance measures suitable for use by hospice and palliative care programs in internal quality improvement efforts (Dy et al., 2015). The final list of ten prioritized measures addresses six of the eight domains of care specified by the National Consensus Project (National Consensus Project for Quality Palliative Care, 2013), and also includes a global measure assessing caregivers' perceptions of care. Work on this initiative continues, with a focus on defining the population of interest for palliative care measures, developing patient-reported, outcomes-based performance measures and measures using electronic specifications, and testing the scientific properties of the measures in the field (AAHPM and HPNA, 2016b).

To address the problem of measurement burden, in 2014, America's Health Insurance Plans and its member plans' chief medical officers, along with the Centers for Medicare & Medicaid Services (CMS), the National Quality Forum (NQF), and other stakeholders, convened the Core Quality Measure Collaborative, an effort to identify core sets of aligned and harmonized performance measures through a consensus-based process (Conway, 2015; CMS, 2016). Payers in this collaboration have committed to using measures in the core sets as soon as is feasible for reporting.

Of the initial seven core measure sets, the Medical Oncology Set (CMS, 2015) is the most salient for palliative and end-of-life care. It includes six measures that assess the quality and

appropriateness of care provided by clinicians for cancer patients who are near the end of life. In a related effort, the Gordon and Betty Moore Foundation and The Pew Charitable Trusts, with the support of Discern Health, recently collaborated on an effort to identify palliative and end-of-life measures that could help seriously ill individuals. Slated to be published in 2017, these recommendations focus on implementing existing quality measures and developing improved tools and measures that can incorporate patient and family feedback.

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***Recently, an NQF-convened Action Team released an issue brief highlighting six key preferences of person-centered advanced illness care.***

The International Consortium for Health Outcomes Measurement (ICHOM) is an important international effort working to transform healthcare systems globally by measuring and reporting clinical and patient-reported outcomes using a standardized approach (ICHOM, 2016). The ICHOM has released several measure sets relevant to palliative and end-of-life care, including sets for cancer, dementia, and care of older persons. The standardized measurement sets provide a valuable resource for monitoring person-centered outcomes in advanced illness care and for benchmarking care across the United States and beyond. They can also serve as the basis for developing performance measures that could be used in value-based improvement programs to assess the quality of care provided for persons near the end of life.

**A Focus on Palliative and End-of-Life Care**

The NQF is a nonprofit, nonpartisan, and membership-based organization that improves health and healthcare quality through measurement and quality initiatives. In 2006, as part of its foundational work in this topic area, NQF convened a multi-stakeholder committee to develop a framework to support future quality

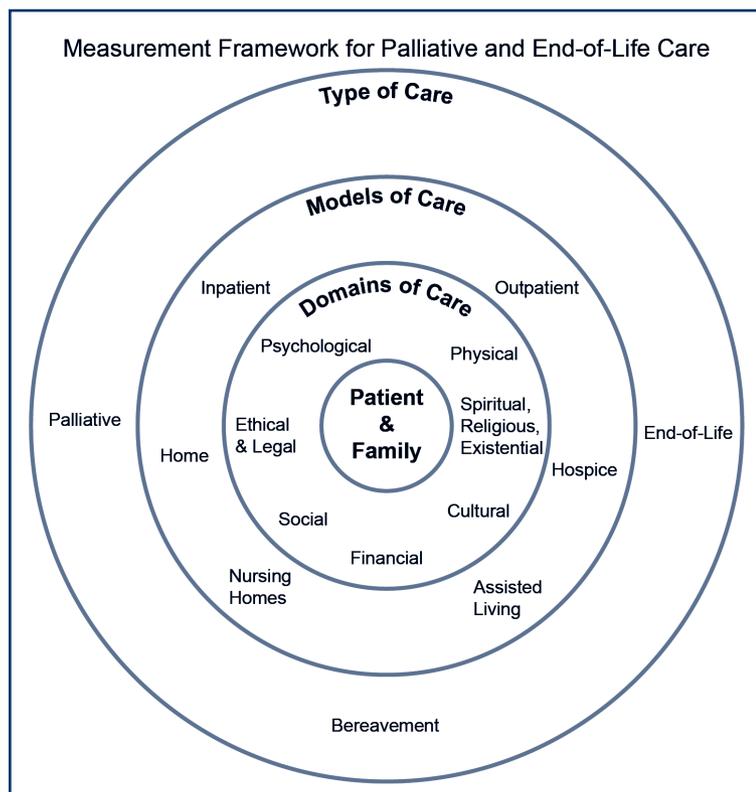
measure development for palliative and hospice care (NQF, 2006). The committee also identified a set of preferred practices to serve as building blocks for providing high-quality care. A decade later, palliative and end-of-life care remains a key focus area for NQF. Key activities include endorsing and selecting performance measures through NQF's core processes, as well as focusing on advanced illness care through NQF's National Quality Partners (NQP).

NQF endorses performance measures through a transparent and consensus-based process, bringing together diverse healthcare stakeholders from the public and private sectors to evaluate measures according to standard criteria for evidence, opportunity for improvement, reliability, validity, feasibility, and usefulness. In 2015, NQF convened a new Palliative and End-of-Life Care Standing Committee to evaluate measures for potential endorsement (NQF, 2015–2016). The Committee includes twenty-five individuals with a remarkable breadth of perspectives—physicians, nurses, pharmacists, chaplains, social workers, employers, payers, and patients.

In October 2016, NQF endorsed twenty-four measures that assess quality of care in relation to physical symptoms, including pain, dyspnea, and constipation; discussion of spiritual or religious concerns; discussion of care and treatment preferences; potentially inappropriate care, such as admission to an ICU or very short lengths of hospice stay; and family experience with hospice care. Several of these measures have been incorporated into the CMS Hospice Quality Reporting Program (HGRP) and/or are included in the Measuring What Matters and Core Quality Measure Collaborative initiatives described above.

Members of the Standing Committee also provided input on a simplified version (see Figure 1, page 89) of the original, comprehensive measurement that was developed in 2006.

**Figure 1. NQF Measurement Framework for Palliative and End-of-Life Care**



Source: NQF. 2015–2016.

Over the next months and years, the Committee will continue to refine the measurement framework, potentially expanding it to include cost, decision making, and safety, as well as help to prioritize gaps in measurement and provide input to advance the science of measurement for palliative and end-of-life care.

Since 2011, NQF has convened the Measure Applications Partnership (MAP), a public-private partnership of more than 150 healthcare leaders and experts, to provide annual input on the selection of performance measures being considered for use in CMS reporting and performance-based payment programs. One of the MAP workgroups provides input on measures considered for inclusion in the HQRP. Another MAP workgroup that focuses on patients dually eligible for Medicare and Medicaid recently

identified key measurement areas that would apply to persons near the end of life. These include goal-directed person-centered care planning and implementation; shared decision-making; systems to coordinate acute care and long-term-care; beneficiary sense of control, autonomy, self-determination, and psychosocial needs; efforts to promote optimal functioning; and community integration and participation (NQF, 2016a).

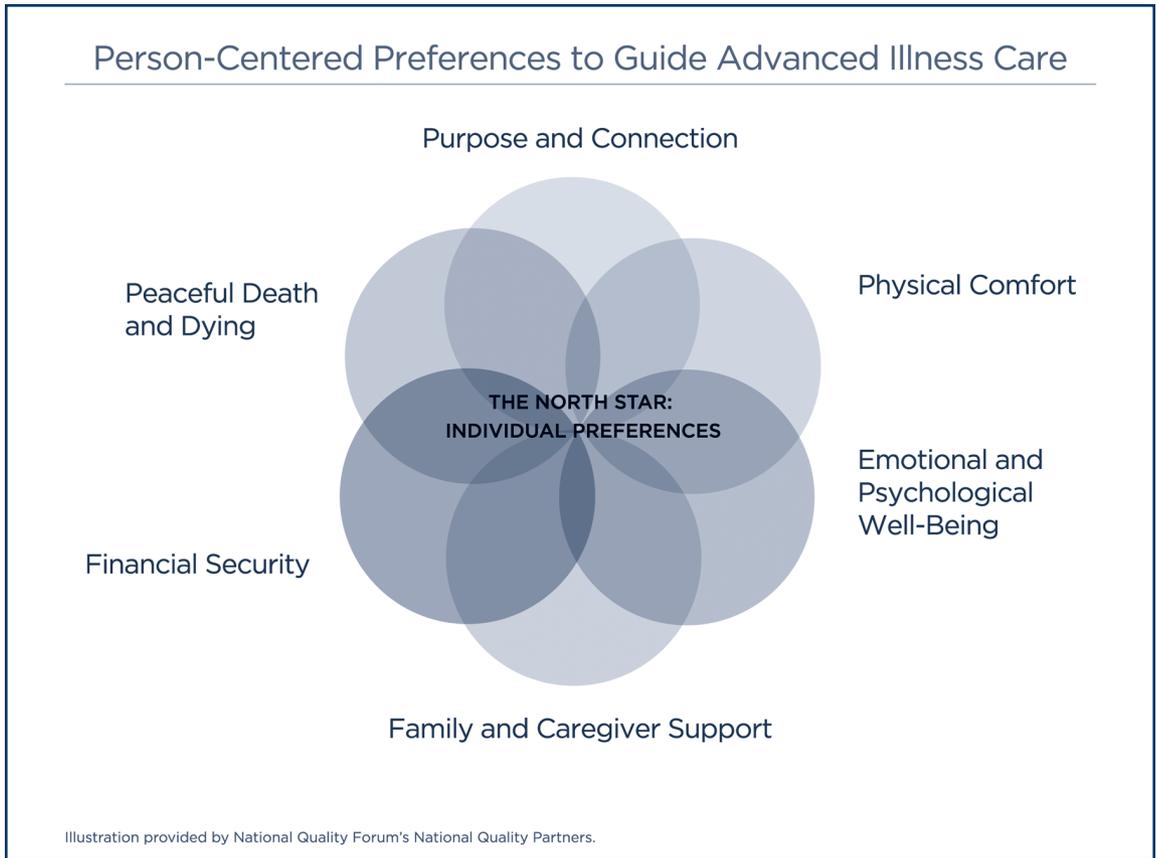
Other related NQF measurement efforts have implications for patients near the end of life, including recent work on measuring home- and community-based services (NQF, 2016a). This seminal report offered a measurement framework, as well as key domains and measurement gaps. Given the shift from inpatient care to care provid-

ed in the community, this broader focus on holistic, community-based care will have significant implications for patients receiving palliative and end-of-life care.

Finally, NQF’s NQP brings together Action Teams that work to advance quality and galvanize action on pressing national healthcare challenges. These groups deliver strategies and tactics advancing policy change, quality measurement, and person-centered approaches to address specific healthcare challenges. Action Team members share concrete examples or best practices, dedicate resources to a particular effort, and identify opportunities for monitoring improvement.

In 2015, the NQF launched its Advanced Illness Care Initiative (NQF, 2016b), an effort guided by an Action Team of more than twenty-five stakeholders from public and private sectors that

**Figure 2. Person-Centered Preferences to Guide Advanced Illness Care**



Source: NQF. 2016c.

is co-led by The Coalition to Transform Advanced Care and Planetree. After convening several webinars and meetings in the past year, the Action Team recently released an issue brief that highlights six key preferences of person-centered advanced illness care (see Figure 2, above), provides examples of measurement opportunities and successes, and identifies opportunities to use measurement to transform advanced illness care, with the goal of empowering individuals with advanced illness, their families, and caregivers to lead decisions about their care.

### **Next-Generation End-of-Life Measures**

Although there are many performance measures that could be used to assess the quality of palliative and end-of-life care, they are frequently

limited by patient condition, setting, or who is being held accountable, and they focus on quality care at a particular point in time only. Moreover, several palliative care and end-of-life measures have not been proven to affect outcomes. For example, while spiritual care is an expected part of high-quality palliative and end-of-life care, studies have not yet demonstrated a link to improved outcomes.

Thus, new and different measures are needed, particularly given the shift to using measures for accountability purposes, especially for value-based payment. Informed by advances in measurement science overall, plus the activities of groups described above, the next generation of measures for palliative and end-of-life care should be as defined on the following page.

- **Person-centered.** Measures that are person-centered are focused on collaborative partnerships among individuals, their defined family, and providers of care. This supports health and well-being by being consistent with, respectful of, and responsive to an individual's priorities, goals, needs, and values (NQF, 2014).
- **Outcomes-focused.** In keeping with the focus on person-centeredness, future palliative and end-of-life measurement should assess patient and-or family outcomes. These measures are of greatest interest to patients, families, and clinicians. These should include measures based on information reported directly by the patient or caregiver without interpretation by a provider (i.e., patient-reported, outcomes-based performance measures). Such measures include experience with care, symptom relief, quality of life, and other health outcomes.
- **Longitudinal.** In contrast to current measures, future measures should be longitudinal in scope, meaning they should assess health and healthcare—and changes in each—within and across settings and over time.
- **Applicable to multiple settings of care.** To the extent possible, given limitations in available data, future measures should be usable regardless of care setting. Achieving this goal likely will be easier for outcome measures such as performance measures based on patient reports.
- **Wider in scope.** Many current measures are limited to a particular patient population, such as hospice patients or patients with advanced cancer, even though the focus of measurement is applicable to a broader target population.
- **Responsive to current gaps in measurement.** The paradigm shift in measurement focused on value necessitates developing measures that can drive the future of palliative and end-of-life care. Some of the gap areas identified by NQF-convened committees include measures that assess symptom man-

agement (not limited to physical symptoms); measures specific to caregivers; measures related to bereavement care; measures that include pediatric and neonatal populations; measures that address the needs of the workforce; and measures that address all settings of care. New models of iterative measure development and testing are needed to more rapidly close these measurement gaps.

### **Measurement: A Powerful Tool to Improve End-of-Life Care**

While performance measurement alone is not sufficient to improve care, it is a powerful tool, particularly when coupled with system redesign and value-based purchasing. The move to assess and reward care based on value across longitudinal episodes should encourage health system innovation that incentivizes more virtual care or home-based care to relieve pain and suffering. The drive to reduce costly hospitalizations, or re-hospitalizations, should increase the perceived value of palliative care as a means for keeping patients comfortable at the most appropriate level of care.

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*Palliative and hospice care may be more cost-effective than inpatient and intensive care, which often go against patients' and family members' preferences.*

Through concerted efforts to improve outcomes and reduce costs, new risk-based alternative payment models should lead to provider collaboration across sites of care. The effectiveness of alternative payment models, such as Accountable Care Organizations and bundled payments, will be judged by improved outcomes and episode-based costs—a particularly salient point given that palliative and hospice care may be more cost-effective than inpatient and intensive care, which often does not meet patient and family members' needs and preferences.

Early insights into measuring advanced payment models suggest a greater role for patient-reported, outcome-based performance measures. Given palliative care's focus on reducing symptom burden, performance measures that help demonstrate improvements in patient symptoms not only reflect a person-centered approach, but also should work to demonstrate the value of system-based approaches.

Finally, a more comprehensive, longitudinal approach to measurement and system redesign should encourage the use of team-based care, including a wide range of providers that can address patients' spiritual and psychosocial needs.

For providers making the leap to risk-based, alternative payment models, these new value-based models present opportunities to drive toward improved care at end of life for their patients. These opportunities may include the following:

- Incorporating holistic, comprehensive palliative care services into longitudinal episodes, such as bundled payments for cancer;
- Promoting interoperable measurement that reflects patient preferences regarding end-of-life treatment across all providers and settings;
- Using team-based care to drive reductions in unnecessary and potentially harmful hospitalizations, re-hospitalizations, and intensive care services;
- Integrating patient-reported, outcomes-based performance measures to assess the effectiveness of alternative payment models (for exam-

ple, reducing symptom burden and/or improving quality of life for persons near the end of life should be rewarded if care that is of high cost and often inappropriate can be avoided);

- Ensuring the voices of families and caregivers are built into evolving models of care and in measurement (e.g., caregiver burden); and
- Defining the population eligible for palliative care, which will help to better target services to at-risk populations and develop appropriate denominators for performance measures that can attribute improved outcomes and lower costs to palliative care services.

## Conclusion

As the nation makes the shift to payment for value over volume, there is an opportunity to weave the most innovative elements of palliative and end-of-life care—including team-based care, use of community providers, and respect for patient and family preferences—into the overall fabric of value-based healthcare. This shift should also provide an opportunity to demonstrate the value of palliative and end-of-life services. A more person-centric approach is needed for all individuals across the entire healthcare spectrum, and palliative and end-of-life care providers can lead the way. 

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# Policy and Politics to Drive Change in End-of-Life Care: Assessing the Best and Worst Places to Die in America

By Andrew L. MacPherson  
and Ravi B. Parikh

Legislative and regulatory initiatives to foster better advanced illness and end-of-life care are strong beginnings, but much remains to be done.

**W**e face uncertain times in healthcare policy and politics. As healthcare reform efforts of the 115th Congress and the Trump Administration take shape, experts and policy makers grapple with broader, downstream impacts of repealing and replacing the ACA, while determining how to push forward with ongoing bipartisan priorities such as value-based payment and delivery reforms.

Despite the United States spending \$3.4 trillion annually on healthcare, our health outcomes are no better than Organisation for Economic Co-operation and Development nation counterparts (Kocher, 2016), and almost a third of the care in the United States is inappropriate or unnecessary (Smith et al., 2012). Moreover, a small percentage of patients account for a disproportionate amount of healthcare spending (Neuman and Cubanski, 2015). This relatively small percentage of patients often receives treatments

or procedures that are unwanted, unnecessary, or do not align with their previously stated goals, values, and preferences (Institute of Medicine, 2014).

Countless studies have highlighted disparities in the quality, access, and affordability of care across geographic regions. Many reform efforts have been targeted toward reducing disparities in insurance coverage, improving access to preventive services, enhancing price transparency, or driving changes in hospital quality, to name several.

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***‘Almost a third of the care in the United States is inappropriate or unnecessary.’***

Yet, in the midst of the debate regarding healthcare reform, an important issue and area of opportunity has been too often overlooked: improving care for those with advanced ill-

**→ABSTRACT** The United States spends \$3.4 trillion annually on healthcare, but outcomes are suboptimal, and almost a third of the care is inappropriate or unnecessary. A small percentage of patients accounts for a disproportionate amount of spending. Dartmouth Atlas of Healthcare data show serious gaps in the quality of advanced illness and end-of-life care delivery, allowing us to rank best and worst places to die. Such statistics are important for legislative and regulatory changes aiming to address disparities and ensure person-centered care delivery. Implementing initiatives requires a community of stakeholders committed to improving care in advanced illness, as well as culture change. | **key words:** *Dartmouth Atlas of Healthcare, advanced illness, end-of-life care, healthcare disparities, best places to die*

ness. Advanced illness occurs when one or more conditions become serious enough that general health declines, treatments begin to lose their impact, and care becomes more focused on comfort.

Partially as a result of Medicare's and Medicaid's disjointed, patchwork payment methodologies, the population with advanced illness is under-supported, lacks care coordination, and is too often inappropriately readmitted to acute care settings—often against personal care objectives and wishes. And while hospice—a successful and highly popular early interdisciplinary, team-based approach to advanced illness, end-of-life care—continues to play an invaluable role in caring for those with advanced illness and those nearing the end of life, the benefit remains underused and needs modernization (NHPCO, 2015).

### Where Are the “Best Places to Die”?

The disparities in our healthcare system are especially pronounced for those facing advanced illness. Our recently completed independent analysis of Dartmouth Atlas of Healthcare data shows serious gaps in the quality of advanced illness and end-of-life care delivery that allows us to categorize the best—and the worst—places to die in America. These statistics are an important predicate for bipartisan legislative and regulatory changes being considered in Washington, D.C.

According to a recent study, the majority of Americans wish to be in the comfort of their own homes at time of death (National Quality Forum, 2012). Thus, metrics such as “deaths in hospital” and “deaths in intensive care unit (ICU)” can be used to measure the extent to which people are not getting the care they want. Data demonstrate significant regional variation in a variety of important indicators of high-quality advanced illness care, such as the number of hospitalizations within the last six months of life, ICU deaths, or referrals to hospice services.

Using seven metrics as indicators of quality of care (deaths in ICU; deaths in hospital; those

**Table 1. Best and Worst Places to Die in America**

Best Places to Die	Worst Places to Die
Ogden, UT	Miami, FL
Dubuque, IA	Los Angeles, CA
Provo, UT	East Long Island, NY
Cedar Rapids, IA	Stockton, CA
Petoskey, MI	Las Vegas, NV
Grand Junction, CO	Newark, NJ
Sarasota, FL	St. Petersburg, FL
Salt Lake City, UT	Manhattan, NY
Appleton, WI	McAllen, TX
Asheville, NC	Bronx, NY

Source: Authors' analysis of Dartmouth Atlas of Healthcare Data ([www.dartmouthatlas.org/](http://www.dartmouthatlas.org/)).

decedents who had to see ten or more physicians in the last six months of life; decedents who were enrolled in hospice; decedents with thirty-day readmissions for all conditions; Hospital Consumer Assessment of Healthcare Providers and Systems [HCAHPS] survey responses for provider communication; and HCAHPS survey responses for pain management), we analyzed Dartmouth Atlas data from 299 Hospital Referral Regions (HRR) across the country to create a comprehensive ranking of the best places to die in America according to these metrics. Data obtained between 2007 and 2010 were plotted for each region and a “z score” was calculated for each to rank them from best to worst. (See Appendix A on page 100 for more information on the data collection and methods.)

Below is a ranking of the best and worst places to experience advanced illness in America using this system:

To provide more context, listed below are a few statistics demonstrating the geographic disparity in care quality received:

- The “best” twenty places ranged from having 13.9 to 18.7 deaths in hospital per 100 Medicare deaths; the “worst” twenty places ranged

from 27.9 to 37.7 deaths in hospital per 100 Medicare deaths.

- Cedar Rapids, Iowa, had an average of 22 percent of Medicare enrollees seeing ten or more doctors in the last six months of life, compared to 55.2 percent in the Bronx, New York.
- Grand Junction, Colorado, only had 15.5 deaths in hospital per 100 Medicare deaths and had an average of 60.2 percent of Medicare enrollees enrolled in hospice during the last six months of life. (The percentage of Medicare enrollees in hospice during the last six months of life ranged from 19.3 percent to 70.3 percent.)

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### ***Dartmouth Atlas of Healthcare data show serious gaps in the quality of advanced illness and end-of-life care delivery.***

These disparities only tell part of the story. Judging the quality of care by metrics that focus on factors such as deaths in the ICU or hospital setting does not provide a complete picture of the kind of advanced illness care that was delivered when the person was possibly one month, six months, or even two years before death.

Yet these statistics indicate a clear problem exists. The wide disparities in care delivery establish a predicate for developing policy and advocacy at the federal and state levels. Perhaps most importantly, the varied experience in care creates a case for consumer demand for receiving the best advanced illness care possible, rather than accepting the best care available within one's geographic location. Many policy proposals put forth in the past several years aim to resolve this disparity.

#### **Federal Interventions to Address Disparities and Improve Care**

Various legislative and regulatory policy initiatives aim to address disparities and ensure that care delivery adheres to people's goals, values, and preferences—the foundation of high-quality advanced illness care. Table 2 (on page 97) high-

lights key legislation (much of which was bipartisan) introduced in the 114th Congress, to improve care for those with advanced illness.

A larger analysis ([goo.gl/2TbZfv](http://goo.gl/2TbZfv)) of federal legislation, done by the Coalition to Transform Advanced Care (C-TAC) reveals several ways to reduce regional disparities in advanced illness care: help local providers boost staff capacity and training; create uniform quality metrics or standards to measure progress; support national awareness initiatives and remove legal or regulatory barriers to advance care planning and earlier referral to community-based hospice programs; and grant providers the flexibility to innovate within their local communities through unique delivery model designs or funding streams.

Despite strong political headwinds and challenges related to changes to the ACA, lawmakers continue efforts in the 115th Congress to work on a bipartisan basis to reintroduce much of the legislation noted above, as well as new approaches.

#### **Regulatory Interventions**

The passage of legislation is only one step toward reducing disparities in advanced illness care, however. Implementing these initiatives requires a dedicated community of stakeholders who are committed to improving the care for those with advanced illness. From payers to providers and consumers to employers, a diverse set of stakeholders continues to work toward the common goals of improving advanced illness care and promulgating and expanding successful, innovative models of care delivery for this population (Centers for Medicare & Medicaid Services [CMS], 2016, 2017).

#### **Paying for advance-care-planning consultations**

In 2015, Medicare announced that it would begin to reimburse physicians and other qualified health professionals to conduct advance-care-planning conversations with beneficiaries (CMS, 2016). Currently, providers are paid for the ex-

**Table 2. Key Federal Legislation from the 114th Congress to Improve Advanced Illness Care Delivery**

Legislation	Sponsors	Summary
Palliative Care and Hospice Education and Training Act ( <a href="http://goo.gl/I9AuY1">goo.gl/I9AuY1</a> )	<b>S. 2748</b> , Sen. Baldwin (D-WI) <b>H.R. 3119</b> , Rep. Engel (D-NY), Rep. Reed (R-NY), Rep. Cleaver (D-MO)	Focuses on <b>workforce development for palliative and hospice care</b> through development of palliative care and hospice education centers. The bill also establishes a national campaign to inform patients, families, and health professionals about palliative care benefits and services, and directs the National Institutes of Health to expand national research to improve the delivery of palliative care to patients with serious illness.
Personalize Your Care Act 2.0 ( <a href="http://goo.gl/V3GwCK">goo.gl/V3GwCK</a> )	<b>H.R. 5555</b> , Rep. Blumenauer (D-OR), Rep. Roe (R-TN)	Creates an <b>advanced illness management and choices pilot program care model</b> through the Center for Medicare and Medicaid Innovation (CMMI), similar to hospice. It also contains provisions to supply grants for Physician Orders for Life-Sustaining Treatment and to increase public awareness of advance care planning; outlines provisions for advance-care-planning standards for Electronic Health Records (EHR); and addresses portability for advance care directives. The bill directs the Health and Human Services Secretary to develop quality measures relating to end-of-life care, and addresses the need for advance care planning and palliative care education and training.
Compassionate Care Act ( <a href="http://goo.gl/fME9XE">goo.gl/fME9XE</a> )	<b>S. 2961</b> , Sen. Blumenthal (D-CT), Sen. Capito (R-WV)	Provides federal funding to <b>improve advance care planning for providers and consumers</b> , calls for development of end-of-life quality measures, and creates a demonstration project for use of telemedicine services for advance care planning.
Medicare Choices Empowerment and Protection Act ( <a href="http://goo.gl/MDo9eS">goo.gl/MDo9eS</a> )	<b>S. 2297</b> , Sen. Coons (D-DE), Sen. Cassidy (R-LA) <b>H.R. 4059</b> , Rep. Black (R-TN), Rep. Welch (D-VT), Rep. Thompson (D-CA), Rep. Collins (R-NY)	Would allow for a one-time <b>financial incentive of \$75 to Medicare beneficiaries to complete an advance directive</b> , and provides information in the <i>Medicare and You</i> handbook on the importance of advance directives.
Care Planning Act ( <a href="http://goo.gl/ZABUOd">goo.gl/ZABUOd</a> )	<b>S. 1549</b> , Sen. Warner (D-VA), Sen. Isakson (R-GA), Sen. Baldwin (D-WI), Sen. Capito (R-WV), Sen. Collins (R-ME), Sen. Klobuchar (D-MN)	Calls for an <b>advanced illness care coordination services demonstration project through the Center for Medicare and Medicaid Innovation (CMMI)</b> , promotes education on advance care planning, and calls for the development of quality measures to evaluate treatment at the end of life, specifically by looking at whether or not the patient's goals align with the treatment plan, treatment received, and treatment outcomes.
Removing Barriers to Person-Centered Care Act ( <a href="http://goo.gl/p40Vvn">goo.gl/p40Vvn</a> )	<b>S. 3096</b> , Sen. Whitehouse (D-RI), Sen. Warren (D-MA)	Would test a shared-savings payment model in up to <b>twenty eligible entities and would allow these entities to waive certain Medicare requirements/regulations</b> (e.g., coverage of curative care during hospice election period) to improve care for eligible Medicare beneficiaries with advanced illness.
Independence at Home Act ( <a href="http://goo.gl/e7O6gY">goo.gl/e7O6gY</a> )	<b>S. 3130</b> , Sen. Markey (D-MA), Sen. Cornyn (D-TX), Sen. Bennet (D-CO), Sen. Portman (R-OH)	<b>Expands the Independence at Home demonstration program to a nationwide benefit</b> , to provide eligible Medicare beneficiaries with twenty-four hours a day, seven days a week, home-based primary care by an interdisciplinary team of providers.
The Creating High-Quality Results and Outcomes Necessary to Improve Chronic (CHRONIC) Care Act of 2016 ( <a href="http://goo.gl/N9Hw5r">goo.gl/N9Hw5r</a> )	<b>S. 3504</b> , Sen. Hatch (R-Utah), Sen. Wyden (D-OR), Sen. Isakson (R-GA), Sen. Warner (D-VA)	<b>Implements Medicare payment policies designed to improve chronic disease management, streamline care coordination, and improve quality outcomes.</b> Topics: Receiving high-quality care in the home; advancing team-based care; expanding innovation and technology options; identifying the chronically ill population; empowering individuals and caregivers in care delivery; and other such policies.

Source: Legislative Database at [www.congress.gov](http://www.congress.gov).

planation, discussion, and completion of advance directives. There are two CPT (Current Procedural Terminology) codes to do so. The first code is for an initial thirty-minute consultation, and the second is an add-on code for additional thirty-minute time blocks. In 2016, CMS took this further by allowing for telehealth advance care planning consultations (CMS, 2017).

Recent data from CMS show that Medicare spent a mere \$16 million over a period of six months for advance-care-planning consultations. If one assumes that total spending reached \$32 million in 2016, these consultations accounted for approximately 0.01 percent in annual spending for Medicare Part B services—“budget dust” in eyes of analysts and lawmakers. Yet the impact on patient outcomes and quality of life is immeasurable when treatment better aligns with patients’ care preferences (Aleccia, 2017; Congressional Budget Office, 2017). It is a small investment that can lead to drastic improvements in care outcomes across every region in the nation.

While reimbursements were an important first step, the early data show there is much work to be done. How do we ensure the entire care team is fully participatory and responsive to the discussion that the provider has with the patient? How should physicians and other health professionals be trained to have these conversations? How can we ensure that the entire care team communicates and follows the person’s care goals, wishes, and preferences? And how do we ensure that the person arrives at a well-informed, values-based decision? Providing for comprehensive, in-depth conversations between provider and beneficiary is a necessary cornerstone in a broader care model or approach, but best clinical practices must be further supported, especially in terms of training.

#### **The Center for Medicare & Medicaid Innovation**

Via the Center for Medicare & Medicaid Innovation (CMMI), CMS is experimenting with various ways to improve care for older adults with multiple complex chronic conditions. These

pilot projects, if deemed successful by the Health and Human Services Secretary, can be replicated and scaled.

One project being tested is the Medicare Care Choices Model that allows hospice programs to concurrently provide curative and comfort care to Medicare beneficiaries. Based on feedback from providers, CMS has recently improved the model to ensure that it has a real impact on the choice and quality of care a person receives.

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### ***The private sector has for years pursued innovative models of care to support those with advanced illness.***

Another promising pilot is the Independence at Home (IAH) model. The model provides home-based primary care services to Medicare beneficiaries with multiple chronic conditions, while tailoring care to an individual person’s needs and relying on interdisciplinary care coordination. Notably, the IAH payment model is designed to reward providers for higher quality care, while lowering costs for the Medicare program overall (for more information, go to [goo.gl/gS2212](http://goo.gl/gS2212)). Furthermore, one important quality metric measures the level of advance care planning and several metrics survey patient satisfaction, which is particularly important for those with advanced illness. In its fourth year, the demonstration has shown substantial savings to Medicare. Recognizing the success of the model, Congress has extended the demonstration and bipartisan legislation has been introduced to make it a permanent component of the program.

These models allow local and regional providers—those who truly understand the nuances and complexities of the populations they serve—to tailor best practices in advanced illness care to their constituents’ needs.

#### **Medicare Access and CHIP Reauthorization Act**

In addition to the steps being taken by CMS and the models tested through CMMI, there are op-

portunities to enhance our ability to measure and improve the quality of care a beneficiary receives through the implementation of the Medicare Access and CHIP Reauthorization Act (MACRA). MACRA streamlines three major provider quality reporting programs: the Physician Quality Reporting System, Value-Based Payment Modifier system, and Meaningful Use into a single program called the Quality Payment Program. Over the next several years, as CMS continues to refine and develop the quality measures to be reported, stakeholders will have more opportunities to push for new measures that accurately assess quality of care. Under MACRA, providers now have the option of participating in advanced Alternative Payment Models (APM) that shift payment toward risk-based and population-focused structures that incentivize better care management strategies and approaches or in the Merit-based Incentive Payment Program (MIPS). As advanced APMs mature and evolve, they will rely heavily on evidence-based approaches to include caring for the population with advanced illness or those at the end of life in order to meet quality-of-care metrics.

The decrease in administrative burden and greater flexibility in care design offered to providers enables them to devote the appropriate time and resources needed to care for the population with advanced illness.

### **A Snapshot of Private-Sector Innovations**

For years, the private sector has pursued innovative models of care to support those with advanced illness, sometimes through the help of federal funding from the initiatives mentioned above. For example, the Sutter Health Advanced Illness Model and Aetna's Compassionate Care program have led the way in developing care delivery innovations to ensure high-quality care for people with advanced illness (Spettell et al., 2009).

Now early-stage companies like Aspire Health and Narus Health are attempting to provide community-level direct advanced illness

and palliative care, while partnering with payers to identify individuals at risk of declining. Leading hospice programs, especially nonprofit programs, have also begun to provide “upstream” care and robust home-based palliative care. Other private-sector groups have led innovations in key areas of advanced illness care, including interdisciplinary team care, predictive analytics, caregiver support, and concurrent treatment-directed and palliative care (Parikh et al., 2016).

For payers or providers that have not yet developed the robust infrastructure or staffing needed to implement innovative advanced illness care models, technology can help fill the gap. Technologies that support care processes developed by providers, including palliative care, homecare, advance care planning, and others, will help provide seamless transitions in care. Some examples are new interventions such as home-based palliative care services, remote monitoring, applications that allow consumers to easily upload and make official their care wishes, or “hot-spotting” software that uses data to help pinpoint individuals eligible for advanced illness interventions show great promise (Bryan, 2017).

### **Conclusion**

As outlined above, the legislative and regulatory initiatives developed to foster better end-of-life care are strong, sustainable beginnings, but there remains much to be done. Many of the legislative and regulatory approaches are aimed at renewing and strengthening physician–patient communication, returning the focus of care to the person, and ensuring that people do not get caught in a complex, uncoordinated, and fragmented care delivery system. They also target disparities in advanced illness care that currently exist in the United States.

Where do we go from here? Policy changes are not the only answer. We must engage in culture change in the healthcare workforce and further develop sustainable community supports for caregivers and the workforce. As our popula-

## Appendix A. Dartmouth Atlas Study Methods

The June 2012 report from the National Quality Forum to CMS, *Performance Measurement Coordination Strategy for Hospice and Palliative Care* (National Quality Forum, 2012), proposed metrics for assessing end-of-life care fell into the following categories: access/availability of services, patient- and family-centered care, goals and care planning, care coordination, provider competency, and appropriateness/affordability of care. These categories of quality metrics were cross-referenced with the quality metrics available in the Dartmouth Atlas of Healthcare—a claims database focusing on the seriously ill population of beneficiaries who died during the period of measurement.

Using this cross-comparison, seven metrics were chosen as key indicators of quality of care received at the end of life. Data points for each of these metrics were collected from 299 Hospital Referral Regions (HRR) across the country to create a comprehensive “ranking” of the best places to die in America.

According to a recent study, an increasing number of Americans wish to stay at home at the time of death (Gruneir et al., 2007). As such, many of the metrics used in this study—including “deaths in hospital” and “deaths in ICU” reflect this growing desire to age in place. Data for all metrics were taken from the years 2007 to 2010 (pre ACA-implementation) and included the following: deaths in ICU, deaths in hospital, those decedents who had to see ten or more physicians in the last six months of life, decedents who were enrolled in hospice, decedents with thirty-day readmissions for all conditions, HCAHPS survey responses for provider communication, and HCAHPS survey responses for pain management.

A “z score” was calculated for each data point; all seven “z scores” for each HRR were added to give an overall score. All measurements were coded in the same direction—a higher number (of deaths in ICU, readmissions, etc.) meant a lower quality outcome. So, the higher the z score, the lower the overall ranking.

tion ages, such change will become increasingly important. We will succeed as a nation when we ensure that a person’s goals, values, and wishes for care are always honored, and when that principle forms the basis of every care delivery model, approach, or technology. Only then can we build a better healthcare system that ensures the

quality of life, dignity, and best care of every single person. 

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# Patient Preferences, Policy, and POLST

By Judy Thomas  
and Charles Sabatino

How innovations and legislation are transforming advanced illness care in a digital age.

Communication is essential for patient-centered care, particularly during periods of advanced illness. Without some form of explicit communication, friends, family, and healthcare providers are left guessing as to the medical interventions a patient would want, or not want, during a serious illness or at the end of life.

The art and science of documenting healthcare preferences have improved greatly over the past forty years—driven largely by shifts in public policy and societal norms. Recognition of the importance of advance care planning has grown, and the process has shifted from a check-box form to broader conversations between providers and consumers regarding treatment wishes and patient values. A prime example of this shift is Physician Orders for Life-Sustaining Treatment, or POLST. One part communications tool, one part medical process, POLST translates goals of care into actionable orders that can be implemented across all care settings.

While the forms and conversations around advance care planning have evolved (Bomba et al., 2012), the method for storing and accessing this important information has not kept pace—we still largely rely on paper forms, which are

not easily accessible when needed most, as in a medical emergency.

Now, a handful of states that have been considered key leaders in developing policy (with and without legislation) around advance care planning and POLST are blazing the trail on developing electronic registries that hold the promise of providing secure storage and immediate access to patient treatment wishes. But figuring out the right formula for registries to maximize their promise will take time.

This article will detail why and how advance planning documents emerged as policy, how clinical practice responded with POLST, and how states like California have successfully spread its growth. It will also spotlight the future of advance-care-planning portability, using examples from states at the forefront of registry development.

## The Evolution of Documenting Healthcare Preferences

POLST is the result of a shifting evolution in attitudes and practices toward advance care planning that started in the mid-1970s. In 1976, California became the first state to adopt a law that created a living will. The law was inspired by

**→ABSTRACT** The art and science of documenting healthcare preferences have improved greatly over the past forty years—driven by shifts in public policy and societal norms. While the forms and conversations around advance care planning have evolved, the method for storing and accessing this information has not kept pace. But what is the future? Registries hold promise, but discovering the right formula for registries to maximize their promise will take time. | **key words:** *POLST, MOLST, POST, Physician Orders for Life-Sustaining Treatment, advance care planning, advance directive, DNR, living will, Coalition for Compassionate Care of California, National POLST Paradigm Task Force*



a New Jersey Supreme Court decision made the previous year, which allowed the withdrawal of a ventilator from Karen Ann Quinlan, a 21-year-old woman in a persistent vegetative state.

Over the next ten years, California's Directive to Physicians law precipitated a wave of living will legislation across the states. By the mid-1980s, the limited focus of these laws spurred interest in a broader approach—using power of attorney to delegate authority to another person able to make the whole range of medical decisions when the principal becomes unable to do so.

By the end of 1997, every state had some version of a healthcare power of attorney law. Since then, legislative changes affecting living wills and power of attorney have been primarily aimed at combining, integrating, extending, and, occasionally, simplifying them to create more comprehensive planning tools, now commonly known as advance directives.

Historically, advance directive laws emphasized standardized legal forms and restrictions, or what has been characterized as a “legal transac-

tional approach.” Unfortunately, this approach often served to impede, rather than promote, effective advance care planning as consumers and providers were put off by the legal terminology and structure (Fagerlin and Schneider, 2004; Wilkinson, Wenger, and Shurgarman, 2007).

Fortunately, the approach to advance care planning has gradually shifted to one that more appropriately acknowledges the importance of an ongoing and flexible process of communication (Sabatino and Karp, 2011).

In its landmark report, *Approaching Death*, the National Academies of Medicine (formerly known as the Institute of Medicine [IOM]) gave an important boost to the shifting paradigm, by defining advance care planning, as follows:

*Advance care planning is a broader, less legally focused concept than that of advance directives. It encompasses not only preparation of legal documents but also discussions with family members and physicians about what the future may hold for people with serious illnesses, how patients and families want their beliefs and preferences to guide decisions, and what steps could alleviate concerns related to finances, family matters, spiritual questions, and other issues that trouble seriously ill or dying patients and their families (Cassel and Field, 1997).*

This concept of advance care planning began to emerge within a broader cultural shift in healthcare and long-term care that continues today—a move away from a framework of paternalist medicine to one of person- and family-centered care.

#### **POLST: where policy and clinical practice meet**

Advance directives can be very effective at identifying decision makers and outlining patient wishes and priorities. However, translating advance directives into effective care plans for seriously ill persons most likely to face a health crisis can be very challenging for providers. Advance directives do not speak the native language of medicine and are often completed so far in

advance that they are hypothetical or lack the context needed (Castillo et al., 2011). Care plans that speak the language of medicine are called medical orders, and this is what drives behavior in medical settings. Without medical orders, standardized medical protocols usually take over.

In 1991, healthcare innovators in Oregon began to formulate a process that addressed the disconnect between advance directives and the increasing need for clear, effective, and actionable medical orders for persons with serious illness or frailty for whom death within the next year would not be surprising. This is how POLST was born (Bomba et al., 2012).

POLST is a conversation tool that clearly states which level of medical treatment a patient wants toward the end of life; it helps give seriously ill patients more control over their treatment and helps patients talk with their healthcare team and loved ones about their choices. POLST can reduce patient and family suffering and make sure patient wishes are known and honored.

#### **POLST process starts with a conversation**

The POLST process starts with a discussion between the treating clinician and the patient with serious illness or frailty (or the patient's authorized surrogate) to ensure the patient understands their current medical condition and treatment options.

Step two translates those wishes and goals into the language of the medical profession, specifically with a set of medical orders that address high-probability critical decisions, such as the following: cardiopulmonary resuscitation; the level of medical intervention desired in the event of emergency (comfort-focused treatments, do-not-hospitalize, selective treatments, or full treatment); the use of artificial nutrition and hydration; and, in some states, the use of antibiotics and ventilation.

The last steps in the POLST process require providers to ensure that POLST follows the patient across all care settings, that all providers honor POLST, and that POLST be reviewed reg-

ularly, especially when there has been a change in medical condition.

A patient's existing advance-care-planning documents are still important to this process, because the POLST discussion is an extension of the same discussion that created those documents. However, POLST addresses here-and-now circumstances, not a distant, hypothetical medical scenario.

In the paper environment, POLST orders are recorded on a unique, brightly colored form that travels with the patient and is kept at the front of the medical record during hospital admission. But in the electronic world, the potential exists to make POLST accessible anywhere, in any setting, with one click.

Across the United States, POLST is known by a variety of names and acronyms, such as Medical Orders for Life-Sustaining Treatment (MOLST), Physician Orders for Scope of Treatment (POST), and Medical Orders for Scope of Treatment (MOST), to name a few. For purposes of this article, the narrative will stick with POLST. (To learn more about POLST programs around the country, visit [polst.org](http://polst.org).)

By the beginning of 2010, eleven states had adopted some version of POLST, either by legislation or as a consensus standard of practice (Sabatino, 2010). By the end of 2016, that number had escalated to thirty-six states—although only nineteen are “endorsed” by the National POLST Paradigm Task Force, an organization of state POLST programs that has developed voluntary consensus standards for the endorsement of these programs (POLST.org, n.d.).

#### **Advance Care Planning and POLST in California**

The work of the Coalition for Compassionate Care of California and its leadership around implementing POLST in California is a great example of how the shift toward a communications paradigm of advance care planning happens.

The Coalition for Compassionate Care of California grew out of a community-based

project in Sacramento in the mid-1990s, which engaged more than a thousand individuals in a series of public discussions about end-of-life care. This work quickly led to a statewide convening of healthcare professionals, long-term-care associations, state agencies, and consumers to propose ways to improve end-of-life care for residents of California's nursing homes through advance care planning and palliative care. It became clear that in order to have a lasting impact, the task force needed to be a statewide body, and the Coalition was born (Citko, 2014).

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***'Without medical orders, standardized medical protocols usually take over.'***

The Coalition honed its focus on advance care planning for one main reason: no one professional or healthcare institution had taken responsibility for advance care planning in California. Physicians find themselves interpreting advance directives, but often have no role in completing them. Hospitals have an obligation to ask about advance directives, but no responsibility to encourage their completion. Attorneys, emergency responders, and others have a piece of advance care planning, but not the whole picture.

Over the past eighteen years, the Coalition has led the way in ensuring that the healthcare preferences of all Californians are respected and honored by partnering with state agencies, healthcare providers, payors, and consumers on a variety of programs. The Coalition has developed programs to change the culture of advanced illness care in California nursing homes; expanded the cultural humility and competency of healthcare clinicians; empowered people with developmental disabilities to be as engaged as possible in the process of making decisions about their medical care; and continually engaged the public in advance-care-planning conversations and cultural awareness.

Coalitions are well-suited for changing care practices—they bring together a broad range of individuals and organizations to shed light on that which is unseen, to co-create a better future, and, ultimately, to change cultural norms.

**California POLST: A Legislative Model**

In 2008, California passed a key bill in the state's history on healthcare decisions and life-sustaining treatment. Assembly Bill 3000 established POLST into law and gave patients a stronger voice in deciding whether or not they would want life-sustaining treatments when they are seriously ill or approaching the end of life.

The Coalition and its partners then spread POLST in one of the largest, most diverse states faster than in any other state in the country—due in large part to the Coalition's volunteers in local communities. Within the first five years, California acted as follows:

- established POLST legislation in a state statute, and developed a standard form;
- organized twenty-seven community-based coalitions working on POLST at a local level;
- developed a standardized curriculum on the POLST conversation;
- formed a statewide taskforce of stakeholders;
- launched the caPOLST.org website; and
- developed consumer educational materials in a range of languages.

By 2012, 95 percent of California nursing homes had completed POLST forms with residents (Jennings et al., 2016), 65 percent of hospitals had a formal POLST policy, and 75 percent of assisted living facilities had implemented POLST education for staff.

In 2015, the Coalition co-sponsored successful legislation, AB 637 (Campos): *Physicians Orders for Life Sustaining Treatment forms*, which authorized nurse practitioners and physician assistants—under the supervision of a physician and within their scope of practice—to sign POLST forms and make them actionable medical orders. The bill went into effect on

January 1, 2016. Today, California is recognized as a POLST “Mature Status” state by the National POLST Paradigm Task Force and is recognized as one of the most successful programs in the country (California Legislature, 2015a).

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***‘One part communications tool, one part medical process, POLST translates goals of care into actionable orders.’***

The successful implementation of POLST is the result of the Coalition’s unique ability to bring together people with a passion for advance care planning, and spark ideas into action through collaboration and the growth of community-based coalitions.

Nine years later, POLST is widely used across California’s continuum of care and is immediately recognized by emergency medical services and other health providers throughout the state, allowing California’s citizens with serious illness to express their treatment wishes and have those wishes be recognized and honored across multiple care settings. But while POLST use is widespread, more can be done to increase its effectiveness, accessibility, and portability. The next logical step in the evolution for POLST is the establishment of an electronic registry.

**Beyond Paper: POLST Portability in the Digital Age**

California is not the first state to consider an electronic POLST registry: New York, Oregon, and West Virginia already have blazed that trail, and states considering similar portability measures have much to learn from their methods.

While many had championed the idea of a statewide registry, California’s large population, geographic size, and de-centralized emergency medical services environment required a measured approach. Two key elements needed to be in place before moving forward: a strong statewide POLST organization (the Coalition) to drive the effort; and a broad uptake of

POLST within the state’s diverse healthcare community to sustain it.

In 2015, California passed Senate Bill 19 (SB-19): *Physician Orders for Life Sustaining Treatment form: electronic registry pilot*, which authorized a pilot test for an electronic registry (POLST eRegistry Pilot Program) and identified the California Emergency Medical Services Authority (EMSA) as the lead state agency overseeing the POLST eRegistry pilot (California Legislature, 2015b). The Coalition was also chosen as a key partner in the pilot development.

The legislation also has two important mandates for providers: physicians, hospitals, and health information exchange (HIE) networks that practice or operate in one of the two pilot communities must make available to the POLST eRegistry any POLST information currently stored within their system; and physicians, nurse practitioners, or physician assistants who practice or operate in one of the two eRegistry pilot communities are required to submit a copy of a newly completed POLST to the eRegistry Pilot, unless the patient requests otherwise.

Recognizing that state funding opportunities would be limited, SB-19 was amended to clarify that state funding was not required and that in order to proceed, the POLST eRegistry Pilot Project would be privately funded. The California Health Care Foundation (CHCF), a long-time supporter of POLST and advance care planning in California, agreed to fund up to \$3 million for the initial implementation of the POLST eRegistry and pilot testing in two California communities.

The POLST eRegistry Pilot Project officially launched in September 2016 under the direction of project partners CHCF, the Coalition, and California EMSA. Following a request for proposal process, Contra Costa and San Diego counties were chosen as the two communities to test the pilot, and Vynca, LLC, was chosen as the project’s primary technology vendor. The POLST eRegistry Pilot Program law (SB-19) remains in effect only until January 1, 2020, at

which time it will be repealed unless the legislature passes a new statute to delete or to extend that date.

The goal of the pilot project is to demonstrate the successful implementation, use, and sustainability of an electronic POLST eRegistry platform for completed POLST forms to be securely submitted and retrieved by medical providers, including emergency medical responders.

Throughout the project, a professional evaluation team, under contract to CHCF, will work closely with the pilot project team to do the following: collect data; evaluate POLST eRegistry functionality; assess utilization, quality, and impact measures; and conduct continuous quality improvement efforts. The results of the evaluation will also be used to build a business case for possible future statewide expansion, and to develop best practices, which can be shared with other states.

Fortunately, California—and states that follow in its footsteps—do not need to start from scratch in developing a statewide registry. Oregon, West Virginia, and New York have already started on this path. Each state model is unique, and offers lessons to be learned regarding different models and approaches.

#### **Oregon State: portability through state legislation**

Oregon is arguably the best example of a successful POLST registry (<http://orpolstregistry.org>). The registry launched in 2009 after the passage of Oregon House Bill 2009, the Oregon POLST Registry Act (2009). The law provides the authority for state activity and funding. A mix of public funding and private grants have funded enhancements. The Oregon POLST Registry currently houses more than 147,000 active POLST forms, which are accessible by EMTs and other health professionals twenty-four hours a day, seven days a week, through a call center (Oregon POLST Registry, 2016).

Seen as standard-bearer for POLST registries because of its time in operation, it is widely used and researched. The registry is a collaborative

effort between Oregon Health Authority, which has statutory administrative responsibility, and Oregon Health Sciences University, which operates the registry. The registry focuses solely on POLST forms. Because advance directives do not provide actionable medical orders, Oregon chose not to include them in the registry.

#### **New York and West Virginia: portability without legislation**

The New York form is known as Medical Orders for Life-Sustaining Treatment (MOLST). First released in 2010, eMOLST is an electronic form completion and process documentation system for the MOLST form. The eMOLST registry (<http://NYSeMOLSTregistry.com>) was developed without legislation by Excellus BlueCross BlueShield Health Insurance Plans, with initial funding provided by New York State Department of Health. The registry is maintained, funded, and operated by Excellus BlueCross BlueShield. There is no law or mandate to submit completed MOLST forms.

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### ***‘By 2012, 95 percent of California nursing homes had completed POLST forms with residents.’***

The Web-based registry allows eMOLST orders and documentation to be accessed twenty-four hours a day, seven days a week by all users, and a standardized single-sign-on capability is built into the application to ease integration with electronic health record systems and HIEs.

A unique component of eMOLST is that it allows healthcare professionals to access the application to create and complete the review and renewal process of eMOLST forms for patients. Quality control measures designed into the application do not allow incomplete forms, forms with incompatible medical orders, or orders lacking the required documentation to be submitted. Forms completed online using the eMOLST

system are automatically included in the registry, and a copy can be printed for the patient.

The West Virginia form (<http://wvendofofife.org>) is referred to as the Physician Orders for Scope of Treatment (POST). In 2010, the West Virginia e-Directive Registry was established through the West Virginia Health Information Network, an HIE. The registry went live in August 2012. The West Virginia Center for End-of-Life Care operates the West Virginia e-Directive Registry under a state contract, and the Bureau for Public Health under the Department of Health and Human Resources by the West Virginia Legislature provides funding for the Center and Registry.

The West Virginia e-Directive Registry is a Web-based tool allowing consumers and providers to voluntarily submit forms, including POST forms, advance directives, Surrogate Selection Checklists, Combined Medical Power of Attorney and Living Wills, and other related documents. Authorized users have Web-based access to search the registry.

## Conclusion

A properly executed POLST turns an individual patient's goals and wishes into treatment-guiding medical orders. If this information is not immediately accessible during a medical crisis, patients' wishes may not be honored, unnecessary treatment may be provided, and patients and their loved ones may suffer.

Information this important should not be limited to paper forms, which can easily be lost or misplaced, or to independent health provider databases, which cannot be shared.

As POLST awareness has evolved and grown, so must the methods for storing and accessing this information. Given the rapid development of digital technology, it is perhaps not surprising that many are looking to statewide electronic registries as the answer.

However, each state is unique, not just in size, demographics, and regulatory environ-

ment, but also in POLST maturity, health systems structure and support, and community level support. We cannot expect to develop a one-size-fits-all approach to successful POLST registry implementation. However, based on the experiences of Oregon, New York, West Virginia, and now California, we can begin to see important considerations and themes emerge for others who would follow this path, such as the following:

- **Strong leadership from an effective state-wide coalition** is essential for both successful POLST programs and successful registries.
- **The state POLST program must be mature.** Widespread understanding and use of POLST throughout the state supports more rapid population of a POLST registry and adoption of its use.
- **Technology is important, but people are key.** Technology provides the framework for a registry, but people drive its purpose and use. Processes for submitting and retrieving POLST must easily integrate into existing workflow in order to economize resources and increase adoption within health systems.
- **A registry must have a clear purpose.** Prior to development, key questions, such as what information will the registry contain and who will have access, must be considered.
- **Funding must be addressed.** Technology development, implementation, and ongoing operations of a statewide POLST registry require a significant commitment of dollars (Zive and Schmidt, 2012).

For states considering POLST registry development, perhaps the most important question is whether the timing is right for them to move forward. 

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# Advanced Illness Care: Driving the Movement Forward

By Bill Novelli  
and Raca Banerjee

Five priority areas that will create sustainable, positive change in this crucial field of care.

The articles in this issue of *Generations* share a common theme: At the core of high-quality advanced illness care delivery is a basic precept wherein a person's goals, values, and preferences should form the foundation of treatment regardless of setting, diagnosis, or condition.

It is clear from the foregoing articles that there has been significant progress in the field of advanced illness care, and that growing momentum exists to continue improving this critical component of the care continuum—one most people will eventually need.

## ***Giving patients and their families what they want yields across-the-board improvements in advanced illness care.***

Healthcare continues to be a contentious national policy and political issue. But no one can argue with the fact that advanced illness care, including palliative care and hospice, is one of the only delivery system elements in which

giving patients and their families exactly what they want yields across-the-board improvements in care quality, patient and family satisfaction, and cost containment.

To move forward, we must attend to the following five priority areas and act to create sustainable positive change by:

- **Establishing High-Quality Clinical and Community-Based Care Models**

We must ensure that comprehensive advance care planning is a primary driver in every care model, rather than an add-on that may be provided only once or twice in a person's lifetime. Care goals and wishes must be continuously updated and revised to reflect the person's changing priorities and disease trajectory. In addition to comprehensive advance care planning, comprehensive care coordination among settings is crucial to ensuring that all providers associated with the individual's care are connected seamlessly throughout the treatment process. Finally, we

→**ABSTRACT** Advanced illness care, including palliative care and hospice, is one of the only delivery system elements in which giving patients and their families exactly what they want yields across-the-board improvements in care quality, patient and family satisfaction, and cost containment. To move forward, we must attend to the following five priority areas and act to create sustainable positive change by: establishing high-quality clinical and community-based care models; improving professional education and caregiver support; promoting consumer engagement; building strong federal and state policy; and establishing standardized national measures to drive care improvement. | **key words:** *advanced illness care, palliative care, hospice*

must support partnerships between health systems and community- and faith-based organizations to promote care that is tailored for diverse racial and ethnic groups, and that provides spiritual and caregiver support to people and their families.

- **Improving Professional Education and Caregiver Support**

We must prioritize training in advance care planning and palliative treatment methods for all healthcare professionals. This is a critical step in developing a standard interdisciplinary care team approach to handle the complex and evolving physical, emotional, and spiritual needs of each patient. We must also ensure that clinicians are trained to acknowledge and support the crucial, and often forgotten, members of the care team—family caregivers. As AARP CEO Jo Ann Jenkins points out, caregivers face unprecedented demands, and those demands continue to grow. In many cases, people will spend more time and resources in caring for their aging parents than they did in raising their own children.

- **Promoting Consumer Engagement**

We must create cultural change that alters how Americans think about advanced illness and end-of-life care. Consumers should have routine, periodic, ongoing advance-care-planning conversations with providers. Providers should engage in shared and informed decision-making (also called patient- and family-engaged care) with patients and their families to ensure they understand and can act on their care options. We must scale and replicate best practices, and expand programs, such as POLST (Physician Orders for Life-Sustaining Treatment), that can be used during late-stage advanced illness to help drive and direct the care plan.

- **Building Strong Federal and State Policy**

To reduce disparities in the quality, access, and cost of advanced illness care across the United States, federal and state legislation and regu-

lation can help to eliminate barriers to advance care planning and help to scale innovative care models that have been proven to work for people at the end of life. State policy can be an important tool to replicate POLST and other models, and to provide regional, tailored interventions to improve advanced illness care.

- **Establishing Standardized National Measures to Drive Care Improvement**

As Burstin and Johnson observe in their article on page 86, our healthcare system still does not have an accepted standard set of measures to assess whether patients and families are receiving high-value advanced illness care. This means we lack the ability to adequately measure progress and to take effective action to improve care quality. No movement can truly advance without common, agreed-upon performance metrics.

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***We must prioritize training in advance care planning for all healthcare professionals.***

In our introductory article (on page 6), we wrote about how this issue is personal for us all. Everyone has stories about loved ones who may have suffered from inferior care, or who, conversely, thrived until their last breath. That we will all eventually approach the end of life is an undeniable aspect of the human condition, and how we respond to it truly defines us.

The time to act is now: let us work together to drive this movement forward. 

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## The Fiction, Fact, and Mystery of Generation X

Candace Steele Flippin and Peter Whitehouse, **Guest Editors**

Generation X (Gen X) was born in fiction and, from the beginning, has been marked with mystery. The term surfaced in Douglas Coupland's 1991 novel *Generation X: Tales from an Accelerated Culture*. The "X" signified a mystery about who was to follow the baby boomers and what they would be like. Gen Xers remain mysterious, yet are often forgotten. But they are also key to our country's social success, as they are now the emergent leaders in organizational life as baby boomers end the next phases of their lives, whether through retirement or encore careers. How will this generation influence politics and economic systems?

Amid the current threats of climate change, the rapid advances in digital technologies, accumulated tumultuous political forces, a society reshaped by immigration, and other societal factors, how will Gen Xers respond to these social and cultural changes and shape these forces themselves? How will they transform aging? Articles in this issue of *Generations* offer insights into an understanding of this generation, and how the process of generational identification may be a key to humans' surviving and flourishing in an increasingly complex world.

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## The Field Guide to Managed Care: A Primer

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