

IMPROVING CARE at the END OF LIFE

A Report of the Aspen Institute Health Strategy Group



Foreword by Kathleen Sebelius and Tommy G. Thompson

Edited by Alan R. Weil and Rachel Dolan

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Robert Wood Johnson Foundation

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The mission of the **Aspen Health Strategy Group** is to promote improvements in policy and practice by providing leadership on important and complex health issues. The group is comprised of 23 senior leaders across influential sectors such as health, business, media, technology and is part of the Health, Medicine and Society Program at the Aspen Institute. Co-chaired by Kathleen Sebelius and Tommy G. Thompson, both former governors and former U.S. Secretaries of Health and Human Services, the Aspen Health Strategy Group tackles one health issue annually through a year-long, in-depth study. This book is a collection of papers on the group's first subject: care at the end of life. The papers address topics related to financing, care delivery and ethics and include a final consensus report based on the group's work.

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December 2016

It is my great pleasure to introduce this inaugural publication of the Aspen Health Strategy Group (AHSI). A new project of our Health, Medicine and Society Program, the Aspen Health Strategy Group is co-chaired by former U.S. Secretaries of Health and Human Services Kathleen Sebelius and Tommy G. Thompson. The group is comprised of 23 senior leaders across influential sectors.

The AHSI embodies the Aspen Institute's tradition of bringing together thought leaders to exchange ideas about society's most vexing challenges and to identify opportunities to have an impact. The group is tasked with providing recommendations on important and complex health issues to promote improvements in policy and practice.

As a country, we need new ideas to address our difficult and controversial health challenges. Each year, the AHSI will select one issue for a year-long, in-depth study. This year's topic was care at the end of life. The leaders in this group have talent, wisdom and experience and we are honored that they have shared their time and thoughts to bring forth this report.

All best,

Walter Isaacson
President & CEO
The Aspen Institute

Contents

Forward 1
Kathleen Sebelius and Tommy G. Thompson
Aspen Health Strategy Group Co-Chairs

Preface 3
Alan R. Weil
Aspen Health Strategy Group Director

Part 1

ASPEN HEALTH STRATEGY GROUP REPORT

Five Big Ideas to Improve Care at the End of Life 7

Part 2

BACKGROUND PAPERS

Overview of the End-of-Life Experience in the United States 21
Laura C. Hanson, M.D., M.P.H.

Care at the End of Life 39
Diane E. Meier, M.D.

**Financing Care at the End of Life:
Ensuring Access and Quality in an Era of Value-Based Reforms** 61
Haïden Huskamp, Ph.D. and David Stevenson, Ph.D.

**Doing Right By the Seriously Ill:
Ethical Norms for Care Near the End of Life** 83
Mildred Z. Solomon, Ed.D.

Foreword

Kathleen Sebelius
Co-Chair

Tommy G. Thompson
Co-Chair

Every day the American health care system brings treatments, cures, and better health to our families, friends, and colleagues. Yet, the design of the system also places financial burdens on governments, businesses, and patients that are difficult to bear. We are in the midst of unprecedented transformation in how we organize and deliver health care, much of it prompted by changes in how we pay for that care. The need for leadership in health care is greater than it has ever been.

It is in this context that we embraced the task of serving as co-chairs of the new Aspen Health Strategy Group. As former governors and former U.S. Secretaries of Health and Human Services, we know the challenges facing our health system. We invited 23 senior leaders to join us. They come from a number of sectors including health, business, media, and technology, and all have the authority and influence to drive meaningful changes in health policy and practice.

The Aspen Health Strategy Group's mission is to promote improvements in policy and practice by providing leadership on important and complex health issues. For this, our inaugural year, we selected care at the end of life as our topic. We know that current systems of care fail to respect the wishes of many dying people and their families. We also see great innovation in this area from creative health systems, insurers, and clinicians. In June 2016, the Aspen Health Strategy Group met for three days and took on hard questions related to this complex and nuanced challenge.

We are pleased to present the final report from our work, based upon our group's rich discussion. In the tradition of the thought-provoking conversations and dialogue on how to address critical societal issues -- the hallmark of the Aspen Institute -- the report includes five big ideas that will transform the way we provide end-of-life care. In those conversations, we relied heavily upon four

background papers, prepared by subject matter experts. Those papers are included in this compendium as well.

We hope these papers and ideas will spur needed changes and promote improvements in care for Americans approaching the end of life. We look forward to working with all of those who share the same goal.

Preface

Alan R. Weil
Director

Care toward the end of life reflects the best and worst of American health care: amazing medical advances delivered by dedicated clinicians, but often provided in the context of a fragmented health system, with its attendant high costs and poor coordination and communication among clinicians and with patients and their families. While all medical care should be patient-centered, the moral imperative for honoring patient preferences is nowhere as strong as it is as patients approach the end of life.

How can we engage people so we can care for them in ways that honor their preferences—preferences that are likely to change over the course of their life and the course of an illness? How can we design systems that meet people’s medical, social, and spiritual needs whether they are at home, in a hospital, in a nursing home, or elsewhere? How do our insurance and social systems need to change to account for the growing burden of chronic illness as people approach death? What are society’s ethical obligations to the 2.5 million Americans who die each year?

Care at the end of life was the theme for this inaugural year of the Aspen Health Strategy Group. Led by co-chairs Kathleen Sebelius and Tommy G. Thompson, former governors and former U.S. Secretaries of Health and Human Services, a group of 23 senior leaders from across sectors met over the course of three days in Aspen, Colorado in June 2016. Given the personal nature of the topic, the discussions were intense and animated. Despite the varied fields from which the group members were drawn, consensus emerged about the current shortcomings of our system in meeting the needs of those with serious illness. The group ultimately embraced five big ideas to transform care for people with serious illness at the end of life.

This volume represents the work of the Aspen Health Strategy Group’s first year. It begins with the report from the meeting, which presents a brief overview of the subject and then offers five big ideas for improvement. After the report are four background papers that the members relied upon to inform their work.

Each background paper was written by a subject matter expert. Laura Hanson provided an overview on the end-of-life experience in the U.S. Haiden Huskamp and David Stevenson summarized the current state of care financing and how that affects access, quality and cost. Diane Meier provided a portrait of the fragmented care delivery system that fails to meet the needs of today's population. Mildred Solomon described the ethical framework for decision making near the end of life as well as ethical challenges that need addressing. We were fortunate to have four of the authors present for the discussion in Aspen, as well as Mollyann Brodie from the Henry J. Kaiser Family Foundation and Tresa Udem of PerryUdem Research, both of whom provided valuable data about Americans' views on this issue.

Before our meeting, we issued a broad call to the public for their ideas for how to improve care at the end of life. We benefited from all of the ideas, but we particularly want to acknowledge the following individuals and organizations for submitting ideas that made their way, often with modification, into the final five big ideas adopted by the group: Richard Baron, ABIM Foundation; Jon Broyles, The Coalition to Transform Advanced Care; Bruce Chernof, The SCAN Foundation; Ken Davis, Mount Sinai Health System; Rebecca Johnson, Sarah Lawrence College; Mary Killackey, Tulane University; Fran Kritz; Joanne Lynn, Altarum Institute; Stan Massey and Martha Vetter, Transcend Hospice Marketing Group; Douglas Renfield-Miller, GoodEnding Inc.; Linda Ward, Center for Practical Bioethics; and, Nancy Zionts, Jewish Healthcare Foundation.

It took a steady hand to bring the Aspen Health Strategy Group to life. Ruth Katz, Director of the Health, Medicine and Society Program at the Aspen Institute, avoided taking any public credit, but everyone involved in this undertaking felt her tremendous contribution and leadership. I want to personally thank her for her commitment to making this new project a success.

I am also grateful to the three organizations that provided funding to make this work possible. They took a risk on a new group, with a new process, and a complex and challenging topic. We received generous financial support from the Robert Wood Johnson Foundation, the Engelberg Foundation, and the Laurie M. Tisch Illumination Fund. On behalf of the Aspen Health Strategy Group and its staff, I thank them all for their strong support and ongoing commitment to this effort.

ASPEN HEALTH STRATEGY GROUP REPORT

**Five Big Ideas to Improve
Care at the End of Life**

Part 1

“Care for people with serious illness approaching the end of life needs to change. The AHSR offers five big ideas that will help catalyze this change.”

– FIVE BIG IDEAS TO IMPROVE CARE AT THE END OF LIFE REPORT

Five Big Ideas to Improve Care at the End of Life

Background

The way we live and the way we die have changed dramatically over the past fifty years, but the medical and social systems that support us as we approach the end of life have not kept up. Institutions we rely upon -- hospitals, nursing homes, medical schools, Medicare, and others -- have, by and large, failed to evolve sufficiently to reflect the new reality. While leaders in each of these sectors are showing the way to a health care system that supports people and their families as they face advanced illness and death, the pace of change is far too slow. The consequences can be seen in the unneeded suffering of millions of Americans as they experience advanced illness and approach death.

The Aspen Health Strategy Group (AHSO) selected care at the end of life as its topic for discussion in 2016—its inaugural year. This group of leaders in and outside health care spent three days considering the topic with the assistance of subject matter experts who prepared four background papers to frame the conversation. The AHSO emerged with five big ideas to transform care for people with serious illness.

The Aspen Health Strategy Group's mission is to promote improvements in policy and practice by providing leadership on important and complex health issues. Co-chaired by Kathleen Sebelius and Tommy G. Thompson, both former governors and former U.S. Secretaries of Health and Human Services, the AHSO is composed of 23 senior leaders across sectors including health, business, media, and technology. More information about the AHSO can be found on the Aspen Institute website (www.aspeninstitute.org/programs/health-medicine-and-society-program/aspen-health-strategy-group).

Framing The Issue

Each year 2.5 million Americans die. About 8 million people, or 2.5% of the U.S. population, have a serious illness or multiple chronic conditions and functional dependency as they approach the end of life. As Laura Hanson explains in "Over-

view of the End-of-Life Experience in the United States,” the quality of end-of-life care is a major public health concern.

Diane Meier begins “Care at the End of Life” with a reminder that “[o]ur [health care] payment system was designed in the 1960s, when long life with multiple chronic conditions was not the norm.” Medicare benefits largely determine what care is provided and paid for at the end of life because, with more than 70% of deaths occurring among those age 65 and older, Medicare is the predominant payer for end-of-life care. Medicare covers medical services, not the social supports so many people need. The traditional reliance of Medicare on fee-for-service payment supports separate silos of care, and has discouraged care coordination, increased fragmentation, and created incentives for delivery of more services. For patients at the end of life, this means receiving potentially unwanted and unnecessary aggressive interventions that can result in increased hospitalizations with little regard for the patient’s or family’s preferences. Having a care plan or a surrogate to speak for the patient can help, but neither provides a guarantee of better care in a fragmented, unaccountable health care system.

Medicare’s primary coverage of services for those at the end of life is through the hospice benefit. The benefit is limited to individuals with a terminal diagnosis who also meet other specific conditions. A person using the hospice benefit receives care according to a plan that may include medical supplies, an aide or homemaker, a social worker, grief counseling, and other services. But the benefit does not cover all service needs, nor does it cover most long-term services and supports, such as assistance with cooking, bathing, dressing and other activities. Medicare offers little coverage of palliative care -- an interdisciplinary specialty focused on improving quality of life through relief of pain and stress -- outside of the hospice benefit. Palliative care is designed to benefit people with serious illness, even if they do not have a terminal illness.

As causes of death have shifted to the consequences of chronic conditions, the “end of life” is often a slow decline with gradually increased functional dependency. Improved treatment has made diseases such as cancer, once a death sentence with a fairly predictable, rapid decline, a chronic condition with, for many, a long life expectancy and unpredictable likelihood or timing of death. The leading cause of death, heart disease, is now often a long-lasting chronic condition prior to an acute episode leading to death.

Fewer people die in the hospital than in the past, but the shift away from hospitals has led to fragmentation and difficult transitions, as people move to and from their home, a nursing home, a hospital intensive care unit, a rehabilitation unit,

and elsewhere. Hospital visits and use of intensive care just prior to death remain high. As Hanson notes “the intensity and cost of treatment in the final phase of illness continues to increase, strongly suggesting that many patients’ desires for a ‘good death’ are not incorporated into the care systems that serve them in this final phase.”

“The central guiding principle of the United States framework for treatment decision making near the end of life has been a patient’s right to self-determination,” says Mildred Solomon in “Doing Right By the Seriously Ill: Ethical Norms for Care Near the End of Life.” One might imagine that this ethos would create a solid foundation for meeting patient and family needs at the end of life. Advance directives and other forms of advance care planning -- documents designed to capture a patient’s wishes -- are a way for patients to ensure that their wishes and goals are taken into account as they approach the end of life with a serious illness. But, Solomon notes, there are inherent social and cultural barriers to planning for the end of life. Despite decades of promotion, only about a quarter of adults have an advance directive. In a recent shift Medicare announced that it would pay physicians for advance care planning conversations with beneficiaries. Data are not yet available, however, to tell us whether or not this policy has increased uptake.

But the ethical challenges surrounding end-of-life care are more pronounced. “The emphasis on autonomy has not achieved its goal of ensuring truly informed choice,” according to Solomon. This is due to the fragmented approach of considering each intervention one-at-a-time rather than taking a more holistic approach to patient and family preferences and goals. With a broader perspective, patients’ and families’ social, emotional, and spiritual needs rise to be on par with or above their medical needs. Solomon describes how “relational ethics” would place patient choice within the context of the social and emotional needs of patients and their loved ones.

The powerful role financing plays in how Americans experience care at the end of life is affirmed by Haiden Huskamp and David Stevenson in “Financing Care at the End of Life: Ensuring Access and Quality in an Era of Value-Based Reforms.” They begin their paper with these words: “The manner in which end-of-life care services are financed is a key determinant of access, quality, and cost of care delivered to individuals as they approach death.”

Many payers, and particularly Medicare, are moving toward bundled payment models and value-based payment systems. That is, rather than paying individually for each service, a single payment is made for an entire episode of care

(bundle) or tied in some way to the quality of the outcome for the patient (value-based). Medicare is currently testing a new payment model for hospice care. The Medicare Care Choices Model allows beneficiaries to receive hospice support services alongside curative treatment. Under the demonstration, hospice providers are paid a fixed monthly fee per beneficiary to cover some hospice services, while other services are paid separately.

Huskamp and Stevenson note various limitations of the transition to new payment models. Hospice and palliative care are often carved out or left out of other value-based payment reforms, inhibiting their integration into new care and service delivery models. The absence of meaningful quality measures related to end-of-life care makes it difficult to pay for quality or value.

Huskamp and Stevenson also describe the critical role that Medicaid plays in paying for social supports excluded from the Medicare benefit. Yet, Medicaid eligibility is limited to those with the lowest income and fewest assets, coordination between Medicare and Medicaid is weak, and Medicaid's long-term services and supports are designed for people with disabilities and frail elders, but not particularly focused on those with advanced illness nearing the end of life.

Meier outlines a number of barriers to improvements in end-of-life care, but also sees opportunities for improvement. Along with changing what we pay for and how we pay for care, Meier highlights the important role quality measurement must play in motivating change. "When asked what is most important to them, the majority of older persons prioritize remaining independent and free of disabling suffering such as pain, shortness of breath and other sources of symptom distress. They rank 'living longer' last among these 3 priorities." Ultimately, Meier concludes, "[a] major multi-sector financial investment in measure development, testing, and implementation is needed to honor our commitment to assuring quality for the most vulnerable and those least able to advocate for themselves."

What Do Americans Need?

During the AHSG discussions, several principles emerged to guide the group toward ideas that improve care. Those principles are as follows:

- The voice of the patient and family should guide care as people face serious illness and approach death.

All health care should be patient-centered, but no phase of care is more personal than that which occurs as a person approaches death. Preferences regarding

measures to be taken to prolong life, willingness to submit to procedures with highly uncertain outcomes, and how to maintain personal autonomy and dignity are highly variable. The best decision for the patient and family is the one selected by an informed and supported patient and family. And while the term “family” is used in this paper, it is important to note that family members are often not aligned among themselves in their views, and in some instances the patient may prefer that a loved one outside the family unit be the person who guides care.

- Health care institutions should engage patients and their families in determining a course of care and should not provide care that is not needed or not wanted.

Health care institutions should ensure patients are well informed of the health and financial costs and benefits of potential interventions at the end of life. Health care providers should respect the guidance they are given by patients and their families. Effective communication entails more than filling out a form or obtaining a signature. Effective patient-family-provider communication -- combined with coordination among those who provide services -- can reduce unwanted services and procedures. Health care institutions should not provide services that a patient does not want.

- Public and private insurance benefits should reflect the social and coordination needs people have as they experience serious illness and approach death.

Insurance is designed to protect people from the financial risk associated with an unfortunate occurrence and help assure access to needed services. People with serious illnesses often have social and coordination needs that go along with their medical needs. Family members may need respite care, patients may have difficulty preparing their own meals, and navigating complex medical and social systems may exceed the capacity of the patient and family. These needs -- and the resources to pay for them -- are often at least as important to the patient as the need for medical services.

- The health professions workforce should have the skills to provide patient-guided care as a team for patients with serious illness and approaching death.

The growth of palliative care as a specialty and team care as a core competency are promising developments but ones that are proliferating too slowly to meet the rapidly growing needs of an aging population. Medical education has been slow to adapt to evolving patterns of mortality and morbidity.

- Community resources should be supported and engaged to make planning for the end of life a normal part of life.

Preparation for respectful and dignified care at the end of life requires a process that engages people long before they are ill and evolves as their lives and health conditions change. The medical care system's interactions with a patient are too infrequent, and often too focused on a particular acute episode, to bear the full burden of eliciting evolving patient preferences. To be effective, engagement on this issue requires the involvement of a variety of community institutions, such as religious groups, voluntary associations, educational organizations, and others.

Five Big Ideas to Improve Care at the End Of Life

Care for people with serious illness approaching the end of life needs to change. The AHSG offers five big ideas that will help catalyze this change.

1. Build the development and updating of an advance care plan into the fabric of life.

Engaging in advance care planning should be as natural as thinking about one's financial future. An advance care plan (also known as an advance directive or living will) outlines a patient's wishes for treatment when he or she has a serious illness and may be unable to make his or her own decisions or speak for him or herself. The plan may be based upon a template, many of which already exist, or it may be highly tailored to the individual. An alternative is the naming of a proxy—a person who has the authority to make care decisions based upon their knowledge of the patient's wishes. The creation of an advance care plan or the naming of a proxy requires conversations between patients and their families and doctors, other clinicians, and those outside the health care sector. Given the taboos surrounding death and the awkwardness many feel considering and discussing it, a cultural change will require engagement of many sectors.

The AHSG considered a broad array of actions that would normalize the advance care planning process:

- Create a standardized, self-guided advance care planning tool that people can use to orient themselves to the issues involved and begin the process at their own convenience.
- Build incentives into public and private insurance plans to encourage people to develop a plan, particularly at critical points such as the time of enrollment

or at open enrollment. Medicare, in particular, could be designed to require or encourage enrollees and/or their providers to have a plan in place at or near the time of enrollment.

- Integrate planning tools into commonly used technology platforms, such as smart phones.
- Model the importance of advance care plans by having everyone in the health care workforce develop their own, thereby making it easier to initiate a conversation with their patients.
- Encourage large employers to build development of advance care plans into their employee benefits programs.
- Build into all of the above options mechanisms to update the plan at regular intervals and particularly, at the time a person is diagnosed with a serious illness.

2. Redefine Medicare coverage in a way that meets the complex needs of people with serious illnesses.

As the largest payer for services needed by people with serious illnesses and approaching the end of life, Medicare has unique power to shape the organization and delivery of services. Rather than focus exclusively on those with a specific terminal diagnosis, as is required to receive the hospice benefit, Medicare could provide additional benefits to those with advanced illness, defined by the Coalition to Transform Advanced Care (CTAC) as “occurring when one or more conditions become serious enough that general health and functioning decline, and treatments begin to lose their impact . . . a process that continues to the end of life.”

There are two large gaps in Medicare coverage for people with serious illness. Medicare provides no coverage for social supports, including respite for family caregivers (other than a very limited benefit as part of the hospice benefit) and help with activities of daily living. In addition, while covering myriad individual clinical services, Medicare provides no coverage for the types of care coordination that become increasingly important as people’s medical conditions become more complex.

Whatever changes Medicare makes to improve care for those with serious illness must be aligned with the broader movement by Medicare to promote the organization of the health care system into accountable groups -- systems of providers

including hospitals, physicians, clinicians, post-acute facilities and others -- that receive a single payment for an episode of care or to cover the total cost of caring for a defined population. Medicare has several demonstrations promoting this shift, and almost one-third of Medicare enrollees are in Medicare Advantage plans, which receive a fixed monthly payment for each enrollee.

The AHSG considered three changes in Medicare policy that would fill in some of the current gaps in coverage:

- Medicare should include a benefit available to those diagnosed with an advanced illness that provides social supports and care coordination through a defined care team. This new coverage would provide strong incentives for providers of care to people with advanced illness to form into teams organized to meet the needs of patients, thereby reducing the fragmentation that such people often experience. Unlike the Medicare hospice benefit, which is dependent upon a diagnosis of limited life expectancy and the enrollee foregoing curative care, eligibility for this benefit would only depend upon diagnosis with an advanced illness.
- Medicare (and Medicaid) should experiment with models that encourage organized systems of care to invest in changes that yield coordinated, patient-centered care for people with advanced illness. Such investments could include enhanced information technology systems that promote coordination, training for care teams, and improved efforts to understand patient preferences. These experiments could use incentives similar to those being given to Accountable Care Organizations (ACOs) to organize, integrate, and reengineer care within a financial model that creates opportunities for rewards when the system is successful in controlling costs while preserving or improving quality.
- Medicare should test integration of the hospice benefit into Medicare Advantage and other Medicare demonstrations. Leaving out these benefits from new care models provides little incentive for improving efficiency and delivery of care to those with serious illnesses. Integration of the hospice benefit would provide greater opportunities for innovation, care coordination and improvement in care quality.

While all of these options are directed to Medicare, many of the same proposals, or at least the same concepts, can also be applied to commercial insurance.

3. Develop a set of quality metrics related to end-of-life care that can be used for accountability, transparency, improvement, and payment.

Quality measurement and reporting are integral to efforts to improve care for people with advanced illness. Measurement allows patients and payers to demand and reward better performance. Measurement also allows providers to benchmark their own performance and learn from leaders. And measurement is essential as payment models change to determine if those changes yield improvement. Quality metrics related to end-of-life care are also critical to the integration of hospice and palliative care into the broader Medicare financing and delivery reform efforts as mentioned above.

The quality measurement enterprise in health care is always complex, but there are particular challenges in the area of end-of-life care. At the end of life, a primary quality metric is adherence to patient wishes, not adherence to predefined care protocols, as may be the case with more routine matters. Much of what is required to provide high-quality care involves communication and coordination—concepts that can be difficult to measure. And clinical outcomes or improvements in health status, which form the basis for many quality measures, have limited applicability at the end of life.

Federal agencies and independent organizations play a significant role in developing, validating, and proliferating the use of quality measures. Government programs can provide a source of funding for measure development and reporting. Given the critical role of patient and family experience in assessing the quality of care at the end of life, a national effort will be required to finance and build the infrastructure necessary to collect quality data. Such an effort might include:

- Develop and validate a standard measurement set that reflects a patient's preferences and the family's experiences and how well health care and social services support them.
- Develop methods for collecting, reporting, and using end-of-life quality measures across diverse care settings, to enable policymakers and providers to evaluate the effectiveness of different approaches.
- Include end-of-life quality measures in federally-sponsored reporting systems, such as Nursing Home Compare and Hospital Compare, so that patients and families can better select providers on the basis of the quality of care they are likely to receive.

- Develop benchmarking, training and feedback systems to enable providers and care systems to improve the quality of services provided.
- 4. Increase the number and types of health professionals who can meet the growing needs of an aging population.**

Graduate medical education includes little training on the needs of patients in the last years of life. Only about 20% of residents plan to work in primary care and less than 1% of physicians pursue fellowships or training in geriatric or palliative medicine. Access to palliative care is largely dependent on hospitalization, leaving out a large segment of the population that lives at home or in long-term care settings. There is a need to train additional doctors, nurses, nurse practitioners, social workers and others in palliative care. Similarly, payment policies should reflect the diverse array of providers needed to deliver high quality palliative care. Larger bundles of payment may facilitate this shift as organizations allocate their payments across providers without the strictures of the Medicare fee schedule. The gap between workforce needs and realistic supply given current circumstances is so large that a multifaceted approach is necessary.

Improving care for those with serious illness requires addressing shortages of professionals with expertise in geriatrics, palliative care and primary care. Creation and recognition through Conditions of Participation of new provider types, such as Advanced Primary Care Practice (APCP), and payment methods that explicitly cover the costs of multidisciplinary teams, would be powerful levers for bringing more providers into the field by assuring the resources they need to do their jobs effectively. Leadership from Medicare could blaze a trail that Medicaid and private insurers could follow.

The AHSG considered four approaches to address workforce needs:

- Create financial and professional incentives to expand the number of health professionals trained in palliative care.
- Integrate understanding of palliative care into the educational experience of all health professionals.
- Establish interdisciplinary training programs designed to develop teams that are expert in palliative care.
- Expand the types of professionals, including community-based workers, who can play a role in providing patient-centered end-of-life care.

5. Support model communities embracing fundamental change in the design and delivery of care for people with advanced illness.

A care system that meets the social needs of people with complex illness must reallocate resources from clinical care to social supports. Such a transformation involves substantial disruption of existing financial flows, and would typically garner significant opposition from those succeeding in current care models. This opposition can only be overcome if the transformation arises from a social consensus developed at the local level.

The AHSG considered the elements that must be in place at the local level to effectuate such a transformation. In addition to a strong local civil society, communities will need educational tools for the citizenry, and perhaps a standardized curriculum to demystify end-of-life issues and create a common language for discourse. Yet, even with these elements in place, communities are limited in what they can do because of the strong financial leverage of state and national programs, insurers, and health systems.

Given the hurdles communities will face in tackling the challenges associated with redesigning end-of-life care systems, those communities that rise to the challenge should be supported in their efforts, and their successes (and lessons from their failures) should be shared with others attempting the same sorts of changes. Community supports could include national recognition, development of a collaborative network to support such communities, and resources to learn from and teach other communities making similar efforts.

Moving Forward

The Aspen Health Strategy Group hopes that these big ideas will serve as catalysts for changes in policy and practice that yield real improvements in end-of-life care. A broad array of dissemination activities is planned to spread the big ideas contained in this report. The leadership of the AHSG will share this report with officials at the Centers for Medicare and Medicaid Services (CMS), the National Academy of Medicine (which is in the midst of a major initiative related to end-of-life care), and the new Administration.

The AHSG members have committed to examining steps they can take within their own institutions and organizations. They are also looking for opportunities to share these ideas with others in their own sector. Change of the scale needed to reorient care for those with advanced illness to the real wishes and needs of patients and families will require the effort of many. The AHSG has set out to

provide leadership and looks forward to working with all who share their goal of promoting improvements in care for Americans approaching the end of life.

BACKGROUND PAPERS

**Overview of the End-of-Life
Experience in the United States**

Laura C. Hanson, M.D., M.P.H.

Care at the End of Life

Diane E. Meier, M.D.

**Financing Care at the End of Life:
Ensuring Access and Quality in
an Era of Value-Based Reforms**

Haiden Huskamp, Ph.D.
and
David Stevenson, Ph.D.

**Doing Right By the Seriously Ill:
Ethical Norms for Care Near
the End of Life**

Mildred Z. Solomon, Ed.D.

Part 2

“Yet, the intensity and cost of treatment in the final phase of illness continues to increase, strongly suggesting that many patients’ desires for a ‘good death’ are not incorporated into the care systems that serve them in this final phase.”

– LAURA HANSON, M.D., M.P.H.

Overview of the End-of-Life Experience in the United States

Laura C. Hanson, M.D., M.P.H.

Life is pleasant. Death is peaceful. It's the transition that's troublesome.

~ Isaac Asimov *Fantastic Voyage II: Destination Brain* (1987)

When she entered the hospital, ovarian cancer had already transformed her. Her face was drawn, shoulders heaving with effortful breathing, eyes closed with fatigue, belly tensely distended. Every other day or so a physician withdrew fluid from her abdomen, yet it crept inexorably upward into her lungs. Her husband spent many hours nearby, touching her hand or bringing in small comforts. He was her only visitor. One physician briefly noted they were Christian Scientists for whom faith-based healing had failed—they were now asking for help in a medical world previously unfamiliar, and seemingly hostile to them.

When oxygen and fluid removal could no longer support her breathing, she was moved into an intensive care unit. Her husband followed down the hall, but was asked to wait outside during the hours required to place central intravenous lines, monitors, and to intubate and attach her lungs to a ventilator. After prolonged attempts at resuscitation, she died. Then her husband was allowed in the room, where he sat quietly by her body until he left, never speaking to anyone.

Introduction

What is a “good death,” and why does it matter? In the Institute of Medicine’s landmark 1997 report *Approaching Death*, a good death is defined as “. . . one that is free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients’ and families’ wishes; and reasonably consistent with clinical, cultural, and ethical standards” (IOM Committee on Care at the End of Life, 1997). The true story of one death, described above, contains many current realities and opportunities for improved care—unrelieved physical suffering, limited communication about treatment choices, and lack of spiritual

care at a time of existential crisis. While death is inevitable, the location and type of medical care during the dying experience is not. Despite our fundamental human fear of mortality, most people want to know when death is near. Once aware of their impending death, most people desire medical care that attends to physical comfort, while also creating opportunities to address spiritual needs, spend time with loved ones, and ensure the wellbeing of surviving family.

The quality of end-of-life care is a major public health concern. Failure to use patient preferences to guide care results in hospital stays and procedures that do not respect patient goals (Heyland, 2006). Clinical interactions at the end of life focus almost exclusively on the possibility of prolonging life, failing to account for other patient and family goals such as human interaction, autonomy, dignity, and spirituality (Gawande, 2014). Paradoxically, despite this high level of clinical care, many Americans experience uncontrolled pain and suffering while dying. Care at the end of life is delivered at great financial expense to patients, families and society (Berwick, 2012). In response to these problems, improving the quality and value of end-of-life care has been identified by the Institute of Medicine as a national priority (IOM Committee on Approaching Death, 2015).

This paper provides an overview of the current American experience of serious illness and dying. It includes basic information on the end-of-life trajectory, describes how people receive care at the end of life, and discusses needed improvements in those care systems.

Describing Death In America

What Defines “End-of-Life”?

While the term “end-of-life” is in common use, it has no commonly agreed upon definition. To patients and families it typically means the final hours or days of life when death’s inevitability is observable. For clinicians, end-of-life care begins earlier, when they recognize a disease as incurable and largely resistant to medical treatments. For policy analysts, “end-of-life” is often a fixed period prior to death—defined retrospectively after death has occurred.

Who Are We Talking About?

While 2.6 million Americans die each year, 46 million Americans, or 18% of the population, struggle with distressing symptoms and major decisions about the use of life-prolonging treatments (Aldridge, 2015). It is this broader group whose experience is shaped by the care systems that exist for those nearing the

end of life. About 8 million people, or 2.5% of the U.S. population, approach the end of life with chronic or serious illness and functional dependency, making their care particularly costly.

Age of Death

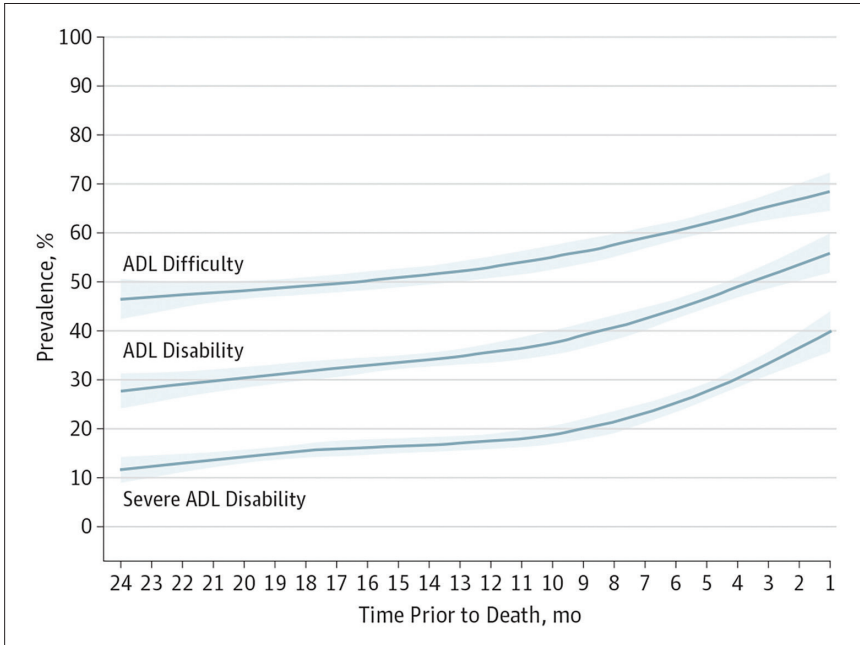
A scientific revolution in public health and medicine has sought to lengthen life, with extraordinary success. In 1900 the average age of death was 48 (IOM Committee on Care at the End of Life, 1997). Development of immunizations, corresponding with public health interventions to improve clean water, nutrition and housing safety all contributed to decreases in infectious disease. The human lifespan increased further due to mid-20th century changes in health care for pregnant women and infants, and development of antibiotics to cure infections. Later technological innovations allowed the modern hospital and intensive care treatments to save lives threatened by acute conditions such as respiratory failure, renal failure or sepsis. Finally, recent medical advances permit early detection and effective management of chronic conditions such as diabetes, heart disease and cancer.

The longevity now seen in developed nations is unprecedented. Within living memory, the dying experience has shifted from middle to late life. The average age of death in the United States is 78.8 years. Seventy-three percent of Americans will live past age 65, and those who reach age 65 typically live into their 80s (Colby, 2015; Murphy, 2016). However, this longevity is not equally accessible, as the gap in life expectancy between the wealthiest and poorest Americans is growing, while racial and ethnic disparities in life expectancy persist (Tavernise, 2016).

Causes of Death

Causes of death in the United States have shifted from acute to chronic conditions. In the early 20th century death commonly occurred from infection, injury, or complications of childbirth—causes resulting in a brief illness before death. In 2013, seven of the 10 most common causes of death in the United States were chronic diseases: heart disease, cancer, chronic lung disease, stroke, Alzheimer’s and other dementias, diabetes and kidney disease (Xu, 2016). Death comes as a result of progression of chronic diseases, which are treated effectively, but not cured, for years. Most of the chronic diseases now causing death result in a slow functional decline with fluctuations of improved and worsened health. The trajectory toward death from chronic diseases includes an extended period of functional dependency, with important implications for supportive services and healthcare (Smith, 2013) (Figure 1).

FIGURE 1: Prevalence of Difficulty, Disability, and Severe Disability in Activities of Daily Living During the Last 2 Years of Life (Smith AK, 2013)



Theoretically, diagnosis of incurable chronic diseases should improve physicians’ awareness of how and when death will occur (Nuland, 1994). This awareness could also facilitate advance care planning, shifts in goals of care, and patient and family preparation for death as the disease progresses. Yet death from chronic diseases also creates an important psychological difference for physicians and patients. Effective treatment of chronic disease exacerbations makes the event of death seem more like a failure of modern medicine than the inevitable outcome of disease. Each exacerbation of congestive heart failure or chronic liver disease seems manageable, and progression of cancer simply triggers the next round of chemotherapy. Death is not optional, but when dying from chronic disease the timing seems much more under the control of modern medicine than it actually is.

Care at the End of Life

Death in hospitals is declining, but end-of-life treatment remains intensive and fragmented. Through the mid-20th century most Americans died at home,

cared for by family and by physicians who made occasional home visits. By the 1970s, spurred by developments in medical treatment and the advent of intensive care units, most people sought end-of-life care in acute care hospitals; death at home became rare (Rothman, 2014). Death in hospitals began to decline again with the shift from per-diem to Diagnosis Related Group (DRG) payments, which establish the level of payment based upon patient diagnosis, regardless of the length of stay (Sager, 1989). By 2009 only 25% of fee-for-service Medicare enrollees died in hospitals, while 28% died in nursing homes and 34% died at home (Teno, 2013).

While extended hospital stays near the time of death may be undesirable, the shift to other settings has increased fragmentation and care transitions during the months leading up to death. A nursing home resident or someone living at home who experiences an acute episode due their worsening chronic condition is often transferred to a hospital intensive care unit that has limited information about the patient. The patient may be discharged to an intermediate care facility prior to returning to his or her residence. Each transition -- between hospital, home, nursing home, or outpatient care -- risks duplication of services and loss of key information. These transitions also take a physical and emotional toll on the patient.

In 2009, 69% of decedents were hospitalized in the last three months of life and 29% were in an intensive care unit in the last month of life. In fact, use of intensive care prior to death continues to increase (Barnato, 2004; Teno 2013). The cause may be structural; intensive care beds are expanding faster than population growth (Wallace, 2015). Demographic trends also favor use of hospital and intensive care near end of life. Epidemiologic analyses show that black race, Hispanic ethnicity, and severely impaired or declining function are associated with more intensive treatment--characteristics of growing subgroups within the United States (Kelley, 2011; Levinsky, 2001; Tschirhart, 2014). In contrast, older age, diagnosis of Alzheimer's or other dementias, or residence in a nursing home is associated with less intensive end-of-life treatment.

Care at the time of death is moving into home and nursing home settings, which may reflect some patient and family preferences to die at home, or to use nursing homes to access 24-hour care when families cannot provide it. Yet, the intensity and cost of treatment in the final phase of illness continues to increase, strongly suggesting that many patients' desires for a "good death" are not incorporated into the care systems that serve them in this final phase.

Emergence of Alternative Models of Care

In response to the medically narrow focus on life-prolonging treatments, palliative care and hospice services began to emerge in the United States in the 1980s. Palliative care is interdisciplinary care, offered at any point in the trajectory of illness, to promote quality of life by providing relief from physical, emotional, social and spiritual suffering for patients with serious illness and their families (National Consensus Project, 2013). Palliative care specialists assist with clarifying goals of medical care, and aligning treatment to patient values and preferences. Some elements of palliative care are now available in 67% of U.S. hospitals (Center to Advance Palliative Care, 2015).

While basic palliative care skills should be expected from most health care providers, the term “specialty palliative care” refers to Hospice & Palliative Medicine board-certified physicians, and palliative care-certified nurses and social workers. Specialty palliative care improves quality of care while lowering hospital costs, particularly when services are accessed early during hospital admission, in nursing homes, or in an outpatient continuing care model (Casarett, 2008; Hanson, 2008; Miller, 2016; Morrison, 2008; Rabow, 2013; Temel, 2010). The workforce of specialty palliative care providers is new, and as yet insufficient. Between 6,000 and 18,000 board-certified palliative care physicians would need to be added to the current 5,500 in practice just to meet existing demand for palliative care services (Lupu, 2010).

Hospice is the primary source of palliative care outside the hospital setting. Hospice teams provide palliative care under a specified payment and regulatory framework. Hospice is available for patients who have a life expectancy of six months or less, and who elect this service while foregoing most life-prolonging medical treatments. In the United States, the hospice delivery system has been largely defined by the introduction of a hospice benefit in Medicare in 1983; most major insurers adopted a similar coverage model. Hospice is available in private homes or specialized hospice inpatient units. It is available in some nursing homes or long-term care settings, but requires a contractual arrangement to coordinate care.

Families report higher quality end-of-life care with hospice, and patients receive improved services for pain management with fewer hospitalizations or intensive treatments (Teno, 2004; Baer, 2000). Hospice does not shorten life, and may result in longer survival for patients with advanced cancer or congestive heart failure (Connor, 2007). Hospice use is increasing—over 40% of Medicare beneficiaries who die enroll in hospice care. However, the median length of stay in hospice

continues to be less than one month, and one-third of hospice patients die within one week of enrollment (National Hospice and Palliative Care Organization, 2015).

Regional Variation in End-of-Life Care

Like other aspects of healthcare, regional practice variation affects the dying experience. Intensive care and hospitalization near death are more common in New York, mid-Atlantic and Southern states, and in southern California, and less common in Midwestern and Western regions. Use of hospice varies widely across states: it is least common in Alaska (24% of deaths) and most common in Arizona (65%) (Dartmouth Atlas, 2016). Studies suggest that regional variation in hospice use is primarily related to supply of healthcare services and local clinical norms, rather than by differences in patient preferences for how they receive end-of-life care (Tschirhart, 2014).

Improving Care at the End of Life

Defining High Quality End-of-Life Care

The future of end-of-life care must be informed by the preferences of patients facing serious illness, and their families. In an early study, patients with serious illness and physical dependency reported they valued pain and symptom management, avoiding prolongation of the dying experience, having a sense of control, relieving burdens for family, and strengthening important relationships as central aspects of this care (Singer, 1999). In a larger study, seriously ill patients, recently bereaved family, and healthcare providers evaluated potential attributes of high quality end-of-life care. All four groups rated pain and symptom management, preparation for death, achieving a sense of completion, decisions about treatment preferences, and being treated as a whole person as highly important elements of end-of-life care (Steinhauser, 2000). After death, surviving families report greater satisfaction with the quality of end-of-life care when hospice is provided than when more intensive treatment is used in an attempt to prolong life (Wright, 2016).

Race, Ethnicity and Culture in End-of-Life Care

Race and ethnicity are associated with differences in end-of-life care preferences and care quality. African-Americans and Latinos are more likely to die in hospitals and to receive intensive treatment near death (Weitzen, 2003; Kelley, 2011; Hanchate, 2009). African-Americans are less likely to enroll in hospice, but Latinos

use this service nearly as often as Americans of European ancestry (Smith, 2009). If these differences result from fully informed choices, they are ethically appropriate. However, clinicians are less likely to engage African-American patients in advance care planning (McKinley, 1996). Potential causes for this communication gap include clinician avoidance behaviors and barriers to health literacy. Structured and culturally tailored information sources show promise as a means to enhance communication (Enguidanos, 2011; Volandes, 2008).

Pain management is essential to high quality end-of-life care, yet patients from minority racial or ethnic groups, compared to the majority white population, report less effective treatment. Compelling evidence from the Eastern Cooperative Oncology Group Minority Outpatient Pain Study found that 65% of Latino and nonwhite patients with pain were given inadequate analgesic prescriptions compared to 50% of white patients (Cleeland, 1994; Cleeland, 1997). Nursing home residents receive less adequate pain treatment if they are African-American (Engle, 1998; Reynolds, 2008). Adequate treatment for pain and suffering is equally important to all patients, regardless of race or ethnic background, making these disparities an important quality concern in end-of-life care.

The concept of a “good death” has cultural as well as individual determinants. While the dominant American culture values individual autonomy, control over treatment decision-making may be less important or even undesirable for some patients. For example, speaking about impending death is considered harmful by traditional Navajos, and truth-telling about prognosis may be less valued in certain Asian cultures (Carrese, 2000; Kagawa-Singer, 2001). In the increasingly diverse U.S. population, models of end-of-life care must be compassionate and culturally informed, to allow flexible approaches to communication, treatment decision-making and preference-sensitive care.

The Challenge of Prognosis

Patients and families must understand prognosis in order to participate in end-of-life decision-making, but current evidence suggests many lack this information (Wolfe, 2000; Weeks, 1998). In general, patients and families want honest information about chances of survival and how illness will affect them in the future, tempered by compassion and awareness of cultural differences in truth-telling (Apatira, 2008). Physicians must be able to address what is known about prognosis, while parsing the uncertainty inherent in the timing of an individual's death.

Diseases with prolonged and fluctuating trajectories do not follow a predictable short-term course toward death, thus limiting physicians' ability to identify a final or terminal phase of the illness. Alzheimer's and other neurodegenerative dementias are the most extreme, causing functional dependency for years punctuated by acute illnesses such as infections or dehydration (Gill, 2010). Tools that add nutritional, functional, and biological variables to diagnosis can assist physicians with probabilistic estimates of patients' life expectancies in a variety of diseases (Yourman, 2012).

According to the SUPPORT Study, which enrolled 9105 seriously-ill hospitalized patients, clinicians estimated a 50/50 chance for two-month survival for patients who died within a week (Lynn, 1997). Further, patients use hope and optimism to interpret prognostic information in individual circumstances. Even physicians have an optimistic bias when communicating patients' life expectancies, further delaying decisions about end-of-life care (Lamont, 2001).

Recommendations

The most important and current resource for defining a path to better quality at the end of life is the Institute of Medicine's 2015 report, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life* (IOM Committee on Approaching Death, 2014). The IOM recommendations are the most recent and comprehensive, from an authoritative source for the U.S.; further, they set an ambitious future standard to help envision what to strive toward. This comprehensive review concludes with five compelling recommendations to transform healthcare for patients with advanced and serious illness, and their families (Figure 2).

These recommendations call for:

- Health care re-design for patients with serious and advanced illness;
- Standards and quality metrics for communication and advance care planning;
- Enhanced training and workforce in palliative care;
- Integration of medical and social services to promote preference-driven care for persons with serious and advanced illness; and
- Broad public outreach to encourage advance care planning.

FIGURE 2: Recommendations from the Institute of Medicine 2015 report *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*

1. Government health insurers and care delivery programs as well as private health insurers should cover the provision of comprehensive care for individuals with advanced serious illness who are nearing the end of life.
2. Professional societies and other organizations that establish quality standards should develop standards for clinician-patient communication and advance care planning that are measurable, actionable, and evidence-based.
3. Educational institutions, credentialing bodies, accrediting boards, state regulatory agencies, and health care delivery organizations should establish the appropriate training, certification, and/or licensure requirements to strengthen the palliative care knowledge and skills of all clinicians who care for individuals with advanced serious illness who are nearing the end of life.
4. Federal, state, and private insurance and health care delivery programs should integrate the financing of medical and social services to support the provision of quality care consistent with the values, goals, and informed preferences of people with advanced serious illness nearing the end of life.
5. Civic leaders, public health and other governmental agencies, community-based organizations, faith-based organizations, consumer groups, health care delivery organizations, payers, employers, and professional societies should engage their constituents and provide fact-based information about care of people with advanced serious illness to encourage advance care planning and informed choice based on the needs and values of individuals.

Beyond the IOM Report, additional recommendations emerge from several major guidelines with more specific audiences. The National Consensus Project for Quality Palliative Care defines optimal practice for health care providers who specialize in palliative care. The National Institute for Health and Care Excellence (NICE) has issued guidelines and practice standards for end-of-life care

in the United Kingdom, and implements tracking data sources to understand how often guidelines are used in practice (NICE 2016). The Hastings Center has published a comprehensive guideline on end-of-life care, with an emphasis on standards for ethical decision-making (Berlinger, 2013). These resources provide additional depth in specific domains, but are not in conflict with the IOM recommendations.

Finally, guidelines are not sufficient to change the experience of end-of-life care. Where are the levers of change? Implementing these recommendations will require pragmatic changes to electronic health records and data systems, to payment and other incentives such as public quality reporting, to the health care workforce and professional training, and to social and practical supports for family caregivers. Critical strategies to facilitate reform include enhanced ability to recognize and track patients with serious and advanced illness within electronic health records, incentives that reward and support clinicians for shared decision-making and communication skills in all healthcare settings, enhanced use of decision aids, policies that incentivize critical workforce training, and quality metrics matched to the needs of persons with serious illness and their families (Austin, 2015; Hanson 2014).

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References

- Aldridge M.D., & Kelley A.S. Appendix E: Epidemiology of serious illness and high utilization of health care, in Institute of Medicine (2015). *Dying in America: Improving quality and honoring individual preferences near the end of life*. Washington, DC: The National Academies Press.
- American Academy of Hospice and Palliative Medicine; Center to Advance Palliative Care; Hospice and Palliative Nurses Association; Last Acts Partnership; National Hospice and Palliative Care Organization. (2004). National Consensus Project for Quality Palliative Care: Clinical Practice Guidelines for quality palliative care, executive summary. *Journal of Palliative Medicine*, 7(5):611-27. <http://www.nationalconsensusproject.org/Default.aspx>
- Apatira, L., Boyd, E.A., Malvar, G., Evans, L.R., Luce, J.M., Lo, B., & White, D.B. (2008). Hope, truth, and preparing for death: perspectives of surrogate decision makers. *Annals of Internal Medicine*, 149,861-868.
- Austin, C.A., Mohottinge, D., Sudore, R., Smith, A.K., & Hanson, L.C. (2015). Tools to promote shared decision-making in serious illness: a systematic review. *Journal of the American Medical Association, Internal Medicine*, 175:1213-21.
- Baer, W.M., & Hanson, L.C. Families' perception of the added value of hospice in the nursing home. *Journal of the American Geriatrics Society* 2000; 48:879-82.
- Barnato, A.E., McClellan, M.B., Kagay, C.R., & Garber, A.M. (2004). Trends in inpatient treatment intensity among Medicare beneficiaries at the end of life. *Health Services Research*, 39, 363-375.
- Berlinger, N., Jennings, B., & Wolf, S.M. (2013). *The Hastings Center guidelines for decisions on life-sustaining treatment and care near the end of life*. Oxford University Press.
- Berwick, D.M. & Hackbarth, A.D. (2012) Eliminating waste in U.S. health care. *Journal of the American Medical Association*, 307,1513-1516.
- Carrese, J.A. & Rhodes, L.A. (2000). Bridging cultural differences in medical practice. The case of discussing negative information with Navajo patients. *Journal of General Internal Medicine*, 15, 92-96.
- Casarett, D., Pickard, A., Bailey, F.A., Ritchie, C., Furman, C., Rosenfeld, K., ...Shea, J.A. (2008). Do palliative consultations improve patient outcomes? *Journal of the American Geriatrics Society*, 56, 593-599.
- Center to Advance Palliative Care & National Palliative Care Research Center. *America's care of serious illness: a state-by-state report card on access to palliative care in our nation's hospitals*. New York, NY 2015. <https://reportcard.capc.org/wp-content/uploads/2015/08/CAPC-Report-Card-2015.pdf>
- Cleeland, C.S, Gonin, R., Baez, L., Loehrer, P., & Pandya, K.J. (1997). Pain and treatment of pain in minority patients with cancer. The Eastern Cooperative Oncology Group Minority Outpatient Pain Study. *Annals of Internal Medicine*, 127(9),813-816.
- Cleeland, C.S, Gonin, R., Hatfield, A.D, Edmonson, J.H., Blum, R.H., Stewart, J.H., & Kandy, K.J. (1994). Pain and its treatment in outpatients with metastatic cancer. *New England Journal of Medicine*, 330(9):592-596.

Colby, S.L., & Ortman, J.M. *Projections of the size and composition of the U.S. population: 2014 to 2060*. U.S. Census Bureau, Ed 2015:25-1143.

Connor, S.R., Pyenson, B., Fitch, K., Spence, C., & Iwasaki, K. (2007). Comparing hospice and nonhospice patient survival among patients who die within a three-year window. *Journal of Pain Symptom Management*, 33,238-246.

Dartmouth Atlas of Healthcare. Retrieved from: <http://www.dartmouthatlas.org/data/topic/topic.aspx?cat=18>

Engle, V.F., Fox-Hill, E., & Graney, M.J. (1998). The experience of living-dying in a nursing home: self-reports of black and white older adults. *Journal of the American Geriatrics Society* 46(9),1091-1096.

Enguidanos, S., Kogan, A.C., Lorenz, K., & Taylor, G. (2011). Use of role model stories to overcome barriers to hospice among African Americans. *Journal of Palliative Medicine*, 14,161-168.

Gawande, A. (2014). *Being Mortal: Medicine and what matters in the end*. New York: Metropolitan Books, Henry Holt and Company.

Gill, T.M., Gahbauer, E.A., Han, L., & Allore, H.G. (2010). Trajectories of disability in the last year of life. *New England Journal of Medicine*, 362, 1173-1180.

Hanchate, A., Kronman, A.C., Young-Xu, Y., Ash, A.S., & Emanuel, E. (2009). Racial and ethnic differences in end-of-life costs: why do minorities cost more than whites? *Archives of Internal Medicine*, 169,493-501.

Hanson, L.C., Schenck, A., & Burstin, H. (2014, January 22). Measuring quality of care for older adults with serious illness. Retrieved from: <http://healthaffairs.org/blog/2014/01/22/measuring-quality-of-care-for-older-adults-with-serious-illness/>

Hanson, L.C., Usher, B., Spragens, L., & Bernard, S. (2008). Clinical and economic impact of palliative care consultation. *Journal of Pain Symptom Management*, 35,340-346

Heyland, D.K., Dodek, P., Rocker, G., Groll, D., Gafni, A., Pichora, D., ... Lam, M. (2006). What matters most in end-of-life care: Perceptions of seriously ill patients and their family members. *Canadian Medical Association Journal* 174(5),627-633.

IOM (Institute of Medicine). (1997). *Approaching death: Improving care at the end of life*. Washington, D.C.: The National Academies Press.

IOM (Institute of Medicine). (2014). *Dying in America: Improving quality and honoring individual preferences near the end of life*. Washington, D.C.: The National Academies Press.

Kagawa-Singer, M., & Blackhall, L.J. (2001). You got to go where he lives: Negotiating cross-cultural issues at the end of life. *Journal of the American Medical Association*, 286(23), 2993-3001.

Kelley, A.S., Ettner, S.L., Morrison, R.S., Du, Q., Wenger, N.S., & Sarkisian, C.A. (2011). Determinants of medical expenditures in the last 6 months of life. *Annals of Internal Medicine*, 154, 235-242.

Lamont, E.B., & Christakis, N.A. (2001). Prognostic disclosure to patients with cancer near the end of life. *Annals of Internal Medicine*, 134(12), 1096-105.

- Levinsky, N.G., Yu, W., Ash, A., Moskowitz, M., Gazell, G., Saynina, O., & Emanuel, E.J. (2001). Influence of age on Medicare expenditures in medical care in the last year of life. *Journal of the American Medical Association*, 286, 1349-1355.
- Lupu, D. (2010). American Academy of Hospice and Palliative Medicine Workforce Task Force. *Journal of Pain Symptom Management*, 40:899-911.
- Lynn, J., Harrell, F. Jr., Cohn, F, Wagner, D., & Connors, A.F. Jr. (1997). Prognoses of seriously ill hospitalized patients on the days before death: Implications for patient care and public policy. *New Horizons*, 5(1),56-61.
- McKinley, E.D., Garrett, J.M., Evans, A.T., & Danis, M. (1996). Differences in end-of-life decision making among black and white ambulatory patients. *Journal of General Internal Medicine*, 11(11), 651-656.
- Miller, S.C., Lima, J.C., Intrator, O., Martin, E., Bull, J., & Hanson, L.C. (2016). Palliative care consults in nursing homes and reductions in acute care use and potentially burdensome end-of-life transitions. *Journal of the American Geriatrics Society*, 64(11), 2280-2287. <http://dx.doi.org/10.1111/jgs.14469>
- Morrison, R.S., Penrod, J.D., Cassel, J.B., Caust-Ellenbogen, M., Litke, A., Spragens, L., & Meier D.E. (2008). Cost savings associated with US hospital palliative care consultation programs. *Archives of Internal Medicine*, 168, 1783-1790.
- Murphy, S.L., Xu, J., Kochanek, K.D., Bastian, B.A., & Kochanek, K.D. (2016). Deaths: Final data for 2013. *National Vital Statistics Reports*, 64,1-119.
- National Consensus Project for Quality Palliative Care. (2013). *Clinical practice guidelines for quality palliative care, 3rd edition*. Retrieved from: www.nationalconsensusproject.org
- National Hospice and Palliative Care Organization, 2015 Facts and Figures. Retrieved from: http://www.nhpc.org/sites/default/files/public/Statistics_Research/2015_Facts_Figures.pdf
- National Institute for Health and Care Excellence. End of life care for adults. Retrieved from: <https://www.nice.org.uk/guidance/qs13/uptake>.
- Nuland, S.B. (1994). *How we die: Reflections on life's final chapter*. New York: A.A. Knopf.
- Rabow, M., Kvale, E., Barbour, L., Cassel, J.B., Cohen, S., Jackson...Weissman, D. (2013). Moving upstream: A review of the evidence of the impact of outpatient palliative care. *Journal of Palliative Medicine*, 16, 1540-1549.
- Reynolds, K.S., Hanson, L.C., Henderson, M., & Steinhauer, K.E. (2008). End-of-life care in nursing home settings: Do race or age matter? *Palliative & Supportive Care*, 6,21-27.
- Rothman, D.J. (2014). Where we die. *New England Journal of Medicine*, 370, 2457-2460.
- Sager, M.A., Easterling, D.V., Kindig, D.A., & Anderson, O.W. (1989). Changes in the location of death after passage of Medicare's prospective payment system: A national study. *New England Journal of Medicine*, 320, 433-439.
- Singer, P.A., Martin, D.K. & Kelner, M. (1999). Quality end-of-life care: Patients' perspectives. *Journal of the American Medical Association*, 281,163-168.
- Smith, A.K., Sudore, R.L., & Perez-Stable, E.J. (2009). Whenever we prayed, she wept: Palliative care for latino patients and their families. *Journal of the American Medical Association*, 301,1047-1057.

Smith, A.K., Walter, L.C., Miao, Y., Boscardin, W.J., & Covinsky, K.E. (2013). Disability during the last two years of life. *Journal of the American Medical Association, Internal Medicine*, 173,1506-1513.

Steinhauser, K.E., Christakis, N.A., Clipp, E.C., McNeilly, M., McIntyre, L., & Tulsky, J.A. (2000). Factors considered important at the end of life by patients, family, physicians, and other care providers. *Journal of the American Medical Association*, 284, 2476-2482.

Tavernise, S. (2016, February 12). Disparity in life spans of the rich and poor is growing. *New York Times*. Retrieved from: http://www.nytimes.com/2016/02/13/health/disparity-in-life-spans-of-the-rich-and-the-poor-is-growing.html?_r=0

Temel, J.S., Greer, J.A., Muzikansky A., ... Lynch, T.J. (2010). Early palliative care for patients with metastatic non small-cell lung cancer. *New England Journal of Medicine*, 363, 733-742.

Teno J.M., Clarridge, B.R., Casey, V., Welch, L.C., Wetle, T., Shield, R., & Mor, V. (2004). Family perspectives on end-of-life care at the last place of care. *Journal of the American Medical Association*, 291(1), 88-93.

Teno, J.M., Gozalo, P.L., Bynum, J.P., Leland, N.E., Miller, S.C., ...Mor, V. (2013). Change in end-of-life care for Medicare beneficiaries: Site of death, place of care, and health care transitions in 2000, 2005 and 2009. *Journal of the American Medical Association*, 309, 470-477.

Tschirhart, E.C., Du, Q., & Kelley, A.S. (2014). Factors influencing the use of intensive procedures at the end of life. *Journal of the American Geriatrics Society*, 62, 2088-2094.

Volandes, A.E., Paasche-Orlow, M., Gillick, M.R., Cook, E.F., Shaykevich, S., Abbo, E.D., & Lehmann, L. (2008). Health literacy not race predicts end-of-life care preferences. *Journal of Palliative Medicine*, 11, 754-762.

Wallace, D.J., Angus, D.C., Seymour, C.W., Barnato, A.E, & Kahn, J.M. (2015). Critical care bed growth in the United States: A comparison of regional and national trends. *American Journal of Respiratory and Critical Care Medicine*, 191, 410-416.

Weeks, J.C., Cook, E.F., O'Day, S.J., Peterson, L.M., Wenger, N., Reding, D., Harrell F.E., ... Phillips, R.S. (1998). Relationship between cancer patients' predictions of prognosis and their treatment preferences. *Journal of the American Medical Association*, 279,1709-1714.

Weitzen, S., Teno, J.M., Fennell, M., & Mor, V. (2003). Factors associated with site of death: A national study of where people die. *Medical Care*, 41, 323-335.

Wolfe, J., Klar, N., Grier, H.E., Duncan, J., Salem-Schatz, S., Emanuel, E.J., & Weeks, J.C. (2000). Understanding of prognosis among parents of children who died of cancer: Impact on treatment goals and integration of palliative care. *Journal of the American Medical Association*, 284, 2469-75.

Wright, A.A., Keating, N.L., Ayanian, J.Z., Chrischilles, E.A., Kahn, K.L., Ritchie, C.S., ... Landrum, M.B. (2016). Family perspectives on aggressive cancer care near the end of life. *Journal of the American Medical Association*, 315, 284-292.

Xu, J., Murphy, S.L., Kochanek, K.D., & Bastian, B.A. (2016). Deaths: final data for 2013. *National Vital Statistics Reports* 2016, 64(2). Retrieved from: www.cdc.gov/nchs/data/nvsr/nvsr64/nvsr64_02.pdf

Yourman, L.C., Lee, S.J., Schonberg, M.A., Widera, E.W., & Smith, A.K. (2012). Prognostic indices for older adults: A systematic review. *Journal of The American Medical Association*, 307,182-192.



“A major multi-sector financial investment in measure development, testing, and implementation is needed to honor our commitment to assuring quality for the most vulnerable and those least able to advocate for themselves.”

– DIANE E. MEIER, M.D.

Care at the End of Life

Diane E. Meier, M.D.

Introduction

Nina Bernstein's 2014 *New York Times* article describes a 91 year-old widower, Joseph Andrey, with multiple chronic conditions, functional dependency and health insurance coverage from both Medicare and Medicaid. His only child is a full-time school teacher who cannot quit work to care for him. The patient has no long-term care insurance nor does his daughter have enough in savings to pay for the personal care he needs in order to be at home. Neither Medicare nor Medicaid will pay for 24/7 personal care. He is cognitively intact, and though his oft-reiterated goal is to be in his own home and to stay there until he dies, instead his last two years of life were characterized by revolving door nursing home stays, hospitalizations, and emergency room visits. He died, in pain from multiple pressure ulcers, several hours after admission to a residential hospice unit. The cost to taxpayers for this period of care neared \$1 million.

What does this story teach us? Our payment system was designed in the 1960s, when long life with multiple chronic conditions was not the norm. Medicare, by statute, covers only that which is "medically necessary," thereby excluding personal care, housing, food, transportation, family caregiver support, and other necessities. Medicaid, a means-tested safety-net insurance program for the poor, covers long-term services and supports for persons who meet the income and functional necessity thresholds, but at much lower levels of payment than are needed, for example, to cover 24/7 personal care supports at home. It is notable that Mr. Andrey was a New York State resident and, despite the fact that New York has the most generous Medicaid program among the 50 states, it was not enough to honor his wish to be at home.

The consequence of this lack of support was a costly series of transitions among nursing home and hospital settings. Mr. Andrey's story is typical and it explains much of the spending on acute care and post-acute "rehabilitation" services, whether or not they are fitted to the goals and needs of patients.

The purpose of this paper is to describe typical patterns and locations of care for the eight million or 2.5% of Americans near life's end, a group defined by occurrence of one or more serious chronic conditions, functional dependency, and falling into the costliest 5% of patients who account for about 60% of all health spending (A. Kelley, et al., 2016; NCHS, 2011). For more detail regarding how this paper uses the term "end of life," see Hanson (in this volume).

Models of Care Near the End of Life

Understanding how patients are cared for during the last few years of life requires examination from diverse perspectives: by patient population; care setting; payer; and via formal (paid) versus informal (unpaid) services and supports.

By Patient Population

Identifying the at-risk population is prerequisite to service design, delivery, and payment. The great majority of deaths (73%) in the U.S. occur during old age (Ortman, Velkoff, & Hogan, 2014). Past efforts to identify those near the end of life have depended largely on prognosis and, as in the design of the Medicare hospice benefit, which requires physician certification that death is expected within six months, assume that accurate prognostication is possible. In cancer, which accounts for only 22% of all deaths, functional decline is a fairly accurate predictor of prognosis. In contrast, functional dependency is a poor predictor of prognosis in the other 78% of deaths—those due to chronic degenerative diseases such as dementia, frailty, and organ system failure. In these diseases, functional decline typically occurs years before death and while it is a marker of end of life as we have defined it here, it is not accurate enough to identify those likely to die in a "short" time. As a result, cancer patients are most likely to die at home with hospice care compared to other diagnostic categories, usually subsequent to an escalating series of hospitalizations in the last months of life. People dying of organ system failure (heart, lungs, kidney, liver) are most likely to die in hospital, at least in part due to the high use of life-prolonging technologies, including transplant, in these categories. Frail elders over age 80 with cognitive and functional impairment are more likely to die in community settings, predominantly nursing homes, assisted living facilities, and private residences, with or without support from hospice.

This variation in location of death by diagnosis is associated with variation in the accuracy of prognostication. If prognosis is not a precise basis for accurate identification of the population near end of life, we are left with disease characteris-

tics, functional status, and prior utilization as the remaining predictors. According to Medicare data, among the costliest 5% of beneficiaries, more than 60% are functionally dependent (Scan Foundation, 2011). Based on several studies, the presence of dementia is a major predictor of both Medicare and Medicaid spending (Callahan, et al., 2015). Persons with severe frailty have roughly a 50% one-year survival rate (Chamberlain, et al., 2016). High symptom burden (e.g., pain, shortness of breath) are predictors both of utilization and of progression of disease (Yang, Ornstein, & Reckrey, 2016).

Based on this literature, predictors of high utilization at end of life include functional dependency, dementia, high symptom distress, frailty, family caregiver stress, one or more serious medical illnesses, and past utilization (A. S. Kelley, et al., 2016; Teno, Gozalo, Bynum, et al., 2013). Given the demography of the high-risk, high-cost patient population and the lack of fit of the design of the current delivery and payment system to their needs, the reasons for overreliance on acute care become clear. If we are to avoid the cycle of rehospitalization in the last months of life, use of predictive analytics based on these characteristics is necessary to match care to patient and family needs.

By Setting

After World War II, the rise in medical science funded by the government, medical specialization, surgical advances, and discovery of new therapies for previously rapidly fatal diseases such as infection, cancer, and heart disease, changed public expectations. Hospitals were the places that provided these new and dramatically effective treatments and hospitals became the preferred place for medical care during serious illness. Growth in the hospital industry followed this rapid pace of discovery, and was catalyzed further by access to health insurance through employment and subsequently, through Medicare and Medicaid legislation. Merely 25 years ago, the majority of deaths occurred in hospitals, a phenomenon that has since declined markedly in concert with the Medicare hospice benefit legislation in 1983, and the shift to prospective payment for hospitals. At present, hospitals are the location of death for fewer than 30% of Americans.

This decrease in hospital deaths hides the fact that most of the deaths occurring outside of hospital are immediately preceded by one or more hospitalizations, often including intensive care unit stays (Teno, Gozalo, Bynum, Leland, et al., 2013). More than 75% of Medicare beneficiaries are in an Emergency Department (ED) at least once in the six months prior to their deaths and most of these ED visits are followed by hospitalization (A. K. Smith, et al., 2012).

The decline in hospital deaths is linked to a contemporaneous increase in home-hospice and nursing home-hospice deaths. The median length of these hospice stays, however, is quite short at 17 days (NHPCO, 2015), suggesting a pattern involving as much acute care as is financially feasible (Medpac, 2016; Teno, Gozalo, Bynum, et al., 2013), followed by hospice care once the imminence of death becomes obvious and when the financial pressures on hospitals, post-acute care providers, and families drive it. Indicators of intensity of care in the last months of life have increased, with a rise in the percentage of beneficiaries receiving care in an intensive care unit during the last month of life from 24.3% in 2000 to 29.2% in 2009 and a rise in the percentage of beneficiaries with three or more hospitalizations in the last 90 days of life from 10.3% to 11.5% (Teno, Gozalo, Bynum, et al., 2013). These statistics also hide wide age-specific as well as regional and state-by-state variation in location of death in the U.S. (IOM, 2015a).

By Payer

Because over 70% of all deaths occur in people over age 65 (NCHS, 2011) and are covered by Medicare, the options for care are heavily determined by what Medicare pays for and what it does not pay for. As noted, Medicare pays generously for ED visits, hospitalizations, specialist care, rehabilitation, and short-term skilled nursing services at home. Those who are also poor and have both Medicaid and Medicare (dual eligibles) are the highest spending subset, using much more long-term nursing home care than other groups, because Medicaid will cover it. Recent state Medicaid policies are trending away from more costly institutional long-term care and towards community-based services and supports, resulting in a shift of care of some dual eligibles back to their homes and communities.

Additional complications are caused by the perverse financial incentives driving transitions from Medicare- to Medicaid-funded settings. In Mr. Andrey's case (Bernstein, 2014), hospitals, capitated by Medicare for each stay, had a financial incentive to discharge him as soon as possible to Medicare-funded rehabilitation units in nursing homes, which, when their 100 days of Medicare coverage were up, had a similar financial incentive to discharge him to a Medicaid-funded nursing home bed, where he would re-admit to a hospital if his needs became complex and/or the goals of his care were unclear to the nursing home staff, thereby restarting the cycle by returning him to a Medicare-funded rehabilitation bed within the same facility. The high cost of these services leave patients at the mercy of administrators who present these care transitions as imperative whether or not they meet the needs of the patient.

The Medicare hospice benefit is designed specifically for those who are predictably dying within six months and who are willing to give up regular insurance coverage for disease treatment. Sixty percent of hospice care is delivered in the beneficiary's place of residence, whether at home, in a nursing home, or an assisted living facility (NHPCO, 2015). Those receiving hospice care in their own homes depend heavily on the availability and capacity of family and other "informal" caregivers to provide for the day-to-day personal care needs of the patient, including medication administration and management, wound care, feeding, dressing, bathing, toileting, and turning and repositioning. Hospice nurses visit every two weeks or so (more often as needed) and are available mostly by telephone in case of a crisis. Satisfaction with hospice care is the highest of all last places of care (Teno, et al., 2004) and both home hospice (Kelley, Deb, Du, Aldridge Carlson, & Morrison, 2013) and nursing home hospice (Unroe, et al., 2016) significantly reduce total Medicare spending.

Predicting the time of death is, at best, challenging in those without cancer, and the majority of patients continue to benefit from disease treatment, in terms of quality of life and functional capacity, until very late in their disease course. As a result, the median length of stay in hospice remains steady at about 17 days, with 35% of beneficiaries receiving hospice for less than a week and 10% for less than a day (NHPCO, 2015). The difficulty of accurate prognostication is especially visible among nursing home residents, the majority of whom have dementia and frailty with high symptom burden for a number of years before their death, which is usually due to a sudden acute and unpredictable infection. The design of the benefit is a poor match to the needs of the population at "end of life" as we defined it here: those with unclear prognosis, long-term palliative care needs, and high formal and informal caregiver burden. The needs of this group have been the main precipitant for the growth in non-hospice palliative care in the U.S.

By Formal (Paid) vs. "Informal" (Unpaid) Care Delivery

Eighty-five percent of care for the population near end of life is delivered by family members and friends. As of 2015, an estimated 65.7 million Americans provided \$470 billion worth of unpaid care to an adult or child in the preceding year. This sum exceeds the combined annual total national costs of formal home care and Medicaid spending. About two-thirds of care recipients are women with an average age of 69.4 years. More than 75% of their caregivers are women, and four in 10 are providing care more than 21 hours per week. The lost income to the caregiver and their family exceeds \$284,000 among male caregivers and

\$304,000 for women. The out-of-pocket spending as a proportion of income and lost wages are especially prolonged and significant for caregivers of persons with dementia (Kelley, et al., 2011) and disproportionately affect minorities and the poor (Alliance, 2016; FCA, 2006).

Our near-total reliance on families for long-term care in the community setting may at first appear to be protective of the taxpayer. If families will provide the care why should government pay for it? This perspective fails to account for the role of the exhausted and overwhelmed family caregiver as the precipitant of the 911 call, leading to the overuse of formal care from hospitals, nursing homes, and home care. A recent study (Callahan, et al., 2012) demonstrating much higher utilization of both Medicare- and Medicaid-funded services among community-dwelling patients with dementia as compared to age-matched controls without dementia, supports this thesis. Further, the stresses and burdens of prolonged caregiving for a functionally impaired and seriously ill loved one translate not only to lost wages and depletion of savings for families; such caregivers also have significantly higher morbidity and mortality (FCA, 2006), adding further to societal health care costs.

Reasons for Current Patterns of Care

Financial Incentives and Disincentives

It is widely acknowledged that the financial incentives and disincentives baked into the Medicare, Medicaid, and commercial insurance worlds account for much of the poor quality and high costs of the U.S. health care system. As we have seen, what is paid for is what patients get independent of its fit to their needs and priorities. Fee-for-service payment, which remains the dominant model, drives over-diagnosis and over-treatment. Lack of meaningful and actionable quality measures makes it difficult to know which hospital stay is preventable and unnecessary and which one reflects best medical care. High reliance on informal care further drives over-utilization of unnecessary and potentially harmful services when such caregivers are overwhelmed, sick themselves, or have no alternative but to call 911 for crisis help after hours or on the weekend.

Reliance on Prognostication as Criterion for Services

The design of the Medicare hospice benefit contributes to inappropriate care in the last several years of life by limiting access only to those people with a predictable and short prognosis who agree to forego disease treatment, thereby

excluding the majority of those with serious illness and functional impairment, who are not predictably dying and who continue to benefit from disease treatment. The resulting short lengths of hospice stay are preceded by high utilization of covered services, such as hospitalization, nursing home rehabilitation services, specialist and emergency department visits (Teno, Gozalo, Bynum, Leland, et al., 2013).

Role of Families

Lack of paid supports for family caregivers results in predictable overuse of covered services, regardless of their fit to the needs of a patient. For example, if a family caregiver is unable to manage a pain or a dyspnea crisis at home and it is after 5 PM or on a weekend, their physician's answering service says "If this is a medical emergency, hang up and call 911." Unless a patient is enrolled in hospice, 24/7 telephone access and home visits when needed are not covered and are not available to the great majority of persons in their last few years of life. When the only way to get help is a 911 call, families call 911.

Training and Lack Thereof Among Clinicians

Though difficult for members of the public to countenance, standard undergraduate and graduate medical and nursing education in the U.S. include little to no content on the needs of patients and their families in the last few years of life. Competencies in pain and symptom management, communication with patients and families about what is most important to them, design of a care plan aligned with these priorities, delivery of well-communicated and coordinated care across settings and over time, and understanding of how to negotiate the health care system on behalf of patients once they are outside of the teaching hospital are not taught, not tested, and not expected of learners.

When a clinician does not know how to safely use opioids for treatment of disabling pain or shortness of breath in an older adult, that patient uses the ED for symptom management. Roughly half of ED visits in those over 65 are due to a distressing symptom (e.g., non-specific chest or abdominal or back pain), most of which are recurrent and chronic (Weiss, Wier, Stocks, & Blanchard, 2011). When a clinician does not know how to initiate or conduct a conversation about what to expect when disease progresses and what matters most to the patient in that context, the conversation does not occur. Instead clinicians provide the care they were trained to give: more hospitalization, more chemotherapy, more consultations, more transfers to the ICU (D. E. Meier, 2014).

A national representative survey of primary and specialty physicians in the U.S. who serve people over age 65, published in April 2016 (JAHF, 2016), found that less than one-third reported any training in conduct of goals of care conversations near the end of life, and nearly half were uncomfortable conducting them. Fewer than one-third reported access to a formal system of reminders, templates or other supports for assessing and recording patients' wishes and goals for care.

Medical and nursing education are designed based upon the requirements for accreditation, a process that is difficult to influence and that has changed little in the last 40 years, despite the growth in number and needs of the chronically ill.

Fragmentation and Hyper Specialization of Medical Care

The last century has seen growth in specialization and a decline in generalist and primary care clinicians (West, 2012; Schwartz, 2012) to where only about 20% of graduating residents in the U.S. plan to work in primary care. The remainder either work as hospitalists or pursue sub-specialization through fellowship training in, for example, oncology, cardiology, and gastroenterology. Approximately 0.2% of physicians pursue fellowship training in either geriatric or palliative medicine, arguably the most needed sub-specialists in the U.S. today. Reasons for this shift towards subspecialization, as cited by trainees, include perceptions about a more controllable lifestyle, work-life balance, paying off medical school debt, and potential income (Phillips, 2009). As a consequence of our lack of primary care infrastructure, a patient with cancer, hypertension, coronary artery disease, diabetes, and arthritic low back pain typically sees four or more subspecialists, none of whom takes on the primary care "quarterback" role. Patients and families must fill this responsibility themselves, often noting that "no-one is in charge." Lack of interoperable electronic health records, inadequate training on provision of coordinated, communicated, continuous care, and lack of accountability for outcomes, compound this error and result in fragmented, redundant, and high-cost care.

What Is To Be Done?

To go from current default -- 911 calls, emergency department visits, and hospitals as the safety net for patients and families -- to a better future state -- reliable coordinated primary care, meaningful 24/7 access to help, and social/medical supports in the home, nursing home and community -- what are the levers?

Rise of the Field of Palliative Care

Palliative care is a relatively new medical and interdisciplinary specialty focused on improving quality of life for people with serious and complex illnesses, and their families. Palliative care clinicians focus on relief of the pain, symptoms, and stresses of serious illness, and work alongside the patient's regular medical team to provide an added layer of support. Palliative care is appropriate at any age, any stage, and any disease type whether the disease is curable, chronic, or progressive and nearing the end of life. Unlike hospice, a model of care designed to serve those that are clearly dying, palliative care eligibility is based on clinical need and not on prognosis.

Studies of palliative care delivery in a range of patient populations, care settings, and countries, consistently show improvement in patient and family quality of life and a subsequent reduction in reliance on emergency services and hospitalization. Several studies among cancer and COPD patients also show improved survival among patients receiving both palliative and best disease care, as compared to patients receiving only usual care alone (Bakitas, et al., 2009; Dionne-Odom, et al., 2015; Higginson, et al., 2014; Temel, et al., 2010). Low-quality and high-cost care are the results of using acute and emergency care to manage predictable and preventable symptom crises, family caregiver exhaustion, and patient and family uncertainty about what to expect and how to manage. A review of more than 40 studies (S. Smith, Brick, O'Hara, & Normand, 2014) found a significant reduction in health care spending among patients receiving palliative care, with or without concurrent disease treatment, as compared to control groups of patients receiving only usual care. Thus, palliative care, by increasing quality in the numerator and decreasing cost in the denominator, is an effective means of improving value for the highest-risk and highest-cost patients.

Access to palliative care in America is variable across geography and care setting. At present in the U.S., besides over 5000 hospices, about two-thirds of U.S. hospitals with more than 50 beds report a palliative care team (CAPC, 2015a; CAPC, 2015b). Because of financial disincentives in the current payment system, there is little access to palliative care for chronically and seriously ill persons who are neither dying nor hospitalized. Since the vast majority of such individuals live either at home or in long-term care settings, the benefits of palliative care need to be expanded to these settings in order to realize its potential to improve value for this large, vulnerable, and costly, group of individuals (Figure 1). Accreditation, regulatory, and quality standards mandating access to palliative care in all care settings are necessary to achieve this goal.

FIGURE 1: The Continuum of Palliative Care



Paying for Value

Both in the U.S. and globally, the organizing principle behind health care policy is strengthening the value equation, or the ratio of quality in the numerator to cost in the denominator. High-value medical interventions such as clean water and vaccination save millions of lives and cost very little per capita. Low-value interventions, such as ICU care for persons with advanced dementia and organ system failure, not only cause suffering and fail to improve quality or length of life, but are also expensive. Because they are sick and need the most medical care, only about 5% of all patients account for 50-60% of total health care spending. Given the vulnerability to suffering and low-value care in these vulnerable populations -- the sickest and costliest 5% -- attention to and measurement of interventions known to improve quality of life and quality of care for this population should be incented, measured, and integrated into the design of health care systems. The desired result is high-value care: better quality of life and care for the highest-risk highest-cost patients (D. E. Meier, 2011; D. E. Meier & Umbdenstock, 2011).

Shifting away from fee-for-service payments that reward volume of services towards paying for value is the dominant strategy for transforming health care in

the U.S. today. This process requires disruption of a \$3 trillion annual industry accounting for 17% of the economy, jobs, and tax base that depends on a fee-for-service business case. The Affordable Care Act represents the single biggest force driving greater assumption of financial risk, accountability for quality outcomes, and control over how health care dollars are allocated by health care organizations and clinicians. The hope is that greater levels of global budgeting and capitation will incent delivery of care well matched to patient and family needs and curb financial incentives driving over treatment and hospitalization.

Palliative care is vital to the success of risk-bearing entities because of the high concentration of health care spending among seriously ill patients and palliative care's ability to improve value for this group.

Changing Training

Given the difficulty of moving entrenched undergraduate and graduate medical and nursing education, government's push for high-value care may be the best strategy for introducing new training requirements. Clinicians must be knowledgeable and skilled in pain and symptom management, geriatric syndromes, social determinants of health, family caregiver assessment and support, and coordinated and well-communicated care across settings and over time, if they are to deliver high-value care required under risk-bearing and value-based payments. The organizations and payers accepting risk may be in the best position to assess these competencies and to require training as a condition of employment.

Rebalancing Resources to Community Settings

At present, the greatest share of health care spending goes to hospitals, imaging and other technologies, pharmaceuticals, specialist visits, and administrative and infrastructure costs associated with a fragmented system (Ginsburg, 2012). These domains are best resourced because they are what is paid for under current policy. To reduce reliance on these sectors, patients and families must have a meaningful and responsive alternative. This is not available now because it is not covered. Karen Davis and others call for just such a change in payment in an April 2016 *Health Affairs* blog (Davis, Willink, & Schoen, 2016) including a new Medicare Help at Home Policy covering up to 20 hours per week of a direct personal care worker for persons with functional and/or cognitive impairment; supported by an accountable Integrated Care Organization responsible for social and medical needs, support for families, and care aligned with beneficiary priorities; and use of innovative team-based care models for beneficiaries at

home. Such a shift of resources away from medical centers and into home and community settings will be gradual because of the economic disruption it will bring, the lack of training in today's workforce to provide such care, and the number of pocketbooks dependent upon the old ways of doing things.

System Redesign, Work Flow Re-engineering

To identify and provide quality care to the sickest, costliest, and most vulnerable patients requires system re-engineering. Examples include routine screening at a population level to identify people with one or more serious illnesses and functional dependency before, not after, they begin to use 911, the Emergency Department, and the hospital as their safety net. Prospective use of predictive analytics requires data not available in the usual claims data sources. Meaningful use requirements should be modified to require electronic health record (EHR) data capture on function, cognition, family caregiver capacity and burden, frailty, and symptom distress, socioeconomic determinants—the factors that are known, in addition to disease types, to predict high need and high utilization (CHCF, 2015; Colbert & Ganguli, 2016). EHRs should take a standardized approach to recording conversations with patients and families about their highest priorities for future care in the context of a progressive illness, and their health care proxy appointee. EHRs must be interoperable if different clinicians working in multiple settings and over time are to understand the issues affecting the patient.

At present, most physicians are measured and compensated based on Relative Value Units (RVUs), a measure of the time and intensity of their work. The time pressures created by this metric create incentives for speed and volume, and inhibit time spent in conversation about patient priorities, time spent in coordination and communication of care across settings, and responsiveness to patient needs outside of typical office visits. A volume incentive is counter-productive for clinicians caring for complex, multimorbid, and functionally and/or cognitively impaired patients. Re-engineering physician incentives to rely on outcomes valued by this population, such as avoiding hospitalization or institutionalization, assessing and supporting family caregivers, relief from pain and symptom distress, preventing bankruptcy due to medical care, and aligning care received to what the patient says is of highest priority, would shift clinicians' focus from volume to value.

Clinician Accountability

The shift from fee-for-service, with its incentives to do too much, to capitation, with its incentives to do too little, necessitates monitoring to prevent under treatment.

Quality measures are supposed to help assure that care is of high quality, and, presumably, prevent under treatment. The current state of quality measurement in the United States could best be described as chaotic (M. E. Porter, S. Larsson, & T. H. Lee, 2016; Reinhardt, 2013), with clinicians held to literally hundreds of different measures, which vary by payer, setting, disease type, and patient population. The frustration, costs, and distraction from caring for patients has led to a re-consideration of these requirements with calls for parsimony, consistency across settings and payers, and use of measures clearly linked to actionable outcomes of importance to patients (IOM, 2015b; M. Porter, S. Larsson, & T. Lee, 2016).

What Accountability Measures Would Improve Care of Those Near End of Life?

Need for Meaningful Quality Outcomes for High-Cost High-Risk Populations

The science of quality measurement is not yet advanced enough to measure what matters most to the sickest and most complex patients, in part because it is difficult to determine preferences, which are not stable and often change over time, and in part because we do not yet have the capacity to apply the resources needed to achieve a patient's top priorities from health care. As in the case of Joseph Andrey (Bernstein, 2014), it is not enough to know our patient's goals. We must also align the supports and resources necessary to honor them. At present, you get what is paid for in the U.S. health care system and what is paid for is ambulance trips, ED visits, hospitalizations, and interventional procedures.

In stark contrast to the U.S., Dame Cicely Saunders, founder of the modern hospice and palliative care movement and of St. Christopher's Hospice in London, spent the last months of her life living at home alone in a three-story row house. She had metastatic cancer to bone and significant pain requiring around-the-clock opioid therapy. Nonetheless, she was able to live by herself in her own home and comfortable until the last few weeks of her life because of what the British call a "tuck-in" service. An aide would arrive each morning to get her up, bathed, dressed and downstairs to the kitchen. The aide would then fix breakfast for Dame Cicely, lay out her medicines for the day, put lunch in the refrigerator, settle her in a chair in the sitting room with phone and remote close to hand, and leave. A hot meal was delivered each evening. At 8 PM each night, another young woman would come and reverse the steps, helping Dame Cicely back up the steps to her bedroom, and tuck her safely into bed. With this minimal support, she remained independent in her own home, as was her wish, until the last few weeks of her life. We do not pay for such services in the U.S.

What measures would help us see that Mr. Andrey's care, though exorbitantly costly, was of poor quality, and that in contrast, Dame Cicely's parsimonious service requirements resulted in much higher quality outcomes? This is the measurement challenge we face.

Goals of Care Among High-Risk Groups

While living a long life is a shared human goal, it is not an unqualified one (D. Meier, 2015). When asked what is most important to them, the majority of older persons prioritize remaining independent and free of disabling suffering such as pain, shortness of breath and other sources of symptom distress. They rank "living longer" last among these three priorities (Fried, et al., 2011). They are concerned about the burdens of their care on their loved ones. They are worried about money and how the cost of their care is compromising the best interests of their family (Singer, Martin, & Kelner, 1999). They seek dignity, the company of the circle of intimates, familiar places, and familiar faces. The health care system, in contrast, focuses predominantly on cure, and on life prolongation. When support for remaining independent with an acceptable quality of life is wanted, health care systems are, to a great degree, helpless. There is more to the ends of medicine than a blinkered focus on disease treatment and survival. There is also the person living with the illness to be considered. What matters most to them? What matters most to their family caregivers?

Patient Satisfaction

Physicians have long assumed that patient and family evaluation of the quality of their care bears no relationship to the actual quality of the care delivered. Recent data suggest that this may not be true (Wang, Tsugawa, Figueroa, & Jha, 2016), as hospital star ratings, consisting of combined scores on patient experience -- including pain management, communication, and timeliness of responses (CAHPS® & Survey, 2015) -- are associated with better patient outcomes, specifically lower mortality rates and fewer readmissions.

Individual clinician ratings, using, for example, the Press-Ganey survey, have been shown to improve care experience as assessed by patients when clinician scores are transparent and visible, initially within the medical center, and later to the general public. The University of Utah moved to public reporting of individual clinician Press-Ganey scores (Lee, 2013) finding a rapid improvement in patient-reported experience of care, presumably resulting from greater physician awareness of how their care affected their patients. Since physician behavior is notoriously resistant to change, this is one among very few levers that has been

consistently shown to change physician behavior. Financial incentives have also been shown to have impact (Clemens & Gottlieb, 2014; D. Meier, 2016).

Measuring What Matters

Everyone agrees we need investment in meaningful, actionable, and valid measures for those approaching the end of life. Yet the goal is honored primarily in the breach. Measurement development and field testing across clinical categories and care settings is costly and time consuming. The palliative care and hospice communities do not have access to sufficient resources. The government has shied away from investing in measure development for this population because of its complexity, cost, and because of a failure of effective political advocacy by the major organizations in the field. Yet the urgency is clear. What will it take to address this quality chasm?

A major multi-sector financial investment in measure development, testing, and implementation is needed to honor our commitment to assuring quality for the most vulnerable and those least able to advocate for themselves. If quality measurement is to achieve its purpose, the industry must tackle the measurement of outcomes that matter to persons at highest risk of neglect, under treatment, over treatment, and suffering for the highest complexity patient populations. This will require collective action from government, the private sector, patient advocacy groups, and clinicians. Collective action requires leadership and coalition building. If we are successful, the care Dame Cicely received (remaining independent at home, social and nutritional needs met, pain and symptoms controlled) would exemplify quality. The care my fellow New Yorker, Mr. Andrey, received (which constitutes usual care in the U.S.) would qualify as a never-event, an exemplar of poor care with real accountability consequences (D. Meier, 2016). Cost containment is urgent and necessary. But so is protection for the patients most in need of care and least able to advocate for themselves.

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References

- Bakitas, M., Lyons, K.D., Hegel, M.T., Balan, S., Barnett, K.N., Brokaw, F.C., et al. (2009). The project ENABLE II randomized controlled trial to improve palliative care for rural patients with advanced cancer: Baseline findings, methodological challenges, and solutions. *Palliative Support Care*, 7(1), 75-86.
- Bass, D., & Noelker, L. (1987). The influence of family caregivers on elders' use of in-home services: An expanded conceptual framework. *Journal of Health and Social Behavior*, 28(2), 184-196.
- Bernstein, N. (2014, September 26). Fighting to honor a father's last wish- To Die at Home. *New York Times*. Retrieved from http://www.nytimes.com/2014/09/26/nyregion/family-fights-health-care-system-for-simple-request-to-die-at-home.html?_r=0
- California Health Care Foundation. (2015). Finding a match: How successful complex care programs identify patients. Retrieved from: <http://www.chcf.org/publications/2015/03/finding-match-complex-care>
- Callahan, C.M., Arling, G., Tu, W., Rosenman, M.B., Counsell, S.R., Stump, T.E., et al. (2012). Transitions in care for older adults with and without dementia. *Journal of the American Geriatrics Society*, 60(5), 813-820.
- Callahan, C.M., Tu, W., Unroe, K.T., LaMantia, M.A., Stump, T.E., & Clark, D.O. (2015). Transitions in care in a nationally representative sample of older Americans with dementia. *Journal of the American Geriatrics Society*, 63(8), 1495-1502.
- Center to Advance Palliative Care. (2015a). America's Care of Serious Illness: 2015 state-by-state report card on access to palliative care in our nation's hospitals. Retrieved May 5, 2016, from <http://reportcard.capc.org/>
- Center to Advance Palliative Care. (2015b). National Palliative Care Registry. Retrieved May 5, 2016, from https://registry.capc.org/cms/portals/1/Reports/Registry_Summary%20Report_2014.pdf
- Centers for Medicare and Medicaid Services. (2015, December 3). National Health Expenditures Data. Retrieved May 2, 2016, from <https://www.cms.gov/research-statistics-data-and-systems/statistics-trends-and-reports/nationalhealthexpenddata/nhe-fact-sheet.html>
- Chamberlain, A., Rutten, L., Manemann, S., Yawn, B., Jacobson, D., Fan, C., et al. (2016). Frailty trajectories in an elderly population-based cohort. *Journal of the American Geriatrics Society*, 64(2), 285-292.
- Clemens, J., & Gottlieb, J. (2014). Do physicians' financial incentives affect medical treatment and patient health? *The American Economic Review*, 104(4), 1320-1349.
- Colbert, J., & Ganguli, I. (2016, May 5). To identify patients for care management look beyond big data. <http://healthaffairs.org/blog/2016/04/19/to-identify-patients-for-care-management-interventions-look-beyond-big-data/>
- Consumer Assessment of Healthcare Providers and Systems (CAHPS®), & Survey, H. (2015). HCAHPS Fact Sheet.
- Davis, K., Willink, A., & Schoen, C. (2016, May 5). Medicare help at home <http://healthaffairs.org/blog/2016/04/13/medicare-help-at-home/>

Dionne-Odom, J.N., Azuero, A., Lyons, K.D., Hull, J. G., Tosteson, T., Li, Z., et al. (2015). Benefits of early versus delayed palliative care to informal family caregivers of patients with advanced cancer: Outcomes from the ENABLE III randomized controlled trial. *Journal of Clinical Oncology*, 33(13), 1446-1452.

Family Caregiver Alliance. (2006). Caregiver health. Retrieved from: <https://www.caregiver.org/caregiver-health>

Family Caregiver Alliance. (2016). Caregiver Statistics: Demographics. Retrieved from: <https://www.caregiver.org/women-and-caregiving-facts-and-figures>

Fried, T.R., Tinetti, M.E., Iannone, L., O'Leary, J.R., Towle, V., & Van Ness, P.H. (2011). Health outcome prioritization as a tool for decision making among older persons with multiple chronic conditions. *Archives of Internal Medicine*, 171(20), 1854-1856.

Ginsburg, P. (2012). *What is driving U.S. health care spending? America's unsustainable health care cost growth*. Retrieved May 5, 2016, from <http://bipartisanpolicy.org/wp-content/uploads/sites/default/files/BPC%20Health%20Care%20Cost%20Drivers%20Brief%20Sept%202012.pdf>

Godwin, K., Morgan, R., Walder, A., Bass, D., Judge, K., Wilson, N., et al. (2014). Predictors of inpatient utilization among veterans with dementia. *Current Gerontology and Geriatrics Research*, 2014. <http://doi.org/10.1155/2014/861613>

Higginson, I.J., Bausewein, C., Reilly, C.C., Gao, W., Gysels, M., Dzingina, M., et al. (2014). An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: A randomised controlled trial. *The Lancet Respiratory Medicine*, 2(12), 979-987.

IOM (Institute of Medicine). (2014). *Dying in America: Improving quality and honoring individual preferences near the end of life*. Washington, D.C.: The National Academies Press.

IOM (Institute of Medicine). (2015b). *Vital Signs: Core metrics for health and health care progress*. Washington DC: National Academy of Sciences.

John A. Hartford Foundation. (2016). Physicians' views toward advance care planning and end-of-life care conversations: Findings from a national survey among physicians who regularly treat patients 65 and older. Retrieved from: http://www.cambiahealthfoundation.org/assets/files/Advance_Care_Report_F_Embargo.pdf

Kelley, A.S., Covinsky, K., Gorges, R., McKendrick, K., Bollens-Lund, E., Morrison, R., et al. (2016). Identifying older adults with serious illness: A critical step towards improving the value of health care. *Health Services Research*. <http://doi.org/10.1111/1475-6773.12479>.

Kelley, A.S., Deb, P., Du, Q., Aldridge Carlson, M.D., & Morrison, R.S. (2013). Hospice enrollment saves money for Medicare and improves care quality across a number of different lengths-of-stay. *Health Affairs*, 32(3), 552-561.

Kelley, A.S., Ettner, S.L., Morrison, R.S., Du, Q., Wenger, N.S., & Sarkisian, C.A. (2011). Determinants of medical expenditures in the last 6 months of life. *Annals of Internal Medicine*, 154(4), 235-242.

Lee, T. (2013). Online reviews could help fix medicine. From <https://hbr.org/2014/06/online-reviews-could-help-fix-medicine/>

MedPAC. (2016). Hospice services. Washington, D.C.: The Medicare Payment Advisory Commission.

Meier, D.E. (2014). 'I don't want Jenny to think I'm abandoning her': Views on overtreatment. *Health Affairs*, 33(5), 895-898.

Meier, D.E. (2011). Increased access to palliative care and hospice services: Opportunities to improve value in health care. *Milbank Quarterly*, 89(3), 343-380.

Meier, D.E. (2016). Measuring quality of care for the sickest patients. Retrieved Feb 9, 2016, from <http://catalyst.nejm.org/measuring-quality-of-care-for-the-sickest-patients/>

Meier, D.E. (2015). Palliative care quality measures: Challenging and urgent. *BMJ Outcomes*. Retrieved from <http://outcomes.bmj.com/index.php/journal/palliative-care-quality-measures-challenging-and-urgent>

Meier, D.E., & Umbdenstock, R. (2011). Palliative care and health delivery reform. *Hospitals & Health Networks*, 85(2), 60.

National Center for Health Statistics. (2011). Death in the United States 2009. Retrieved from <http://www.cdc.gov/nchs/data/databriefs/db64.pdf>.

National Hospice and Palliative Care Organization. (2015). Hospice facts and figures. Retrieved May 5, 2016, from http://www.nhpco.org/sites/default/files/public/Statistics_Research/2015_Facts_Figures.pdf

Ortman, J., Velkoff, V., & Hogan, H. (2014). An aging nation: The older population in the United States. Retrieved from <https://www.census.gov/prod/2014pubs/p25-1140.pdf>

Phillips, R. (2009). Specialty and geographic distribution of the physician workforce: What influences medical student & resident choices?

Porter, M., Larsson, S., & Lee, T. (2016). Standardizing patient outcomes measurement. *New England Journal of Medicine*, 374(6), 504-506.

Reinhardt, U. (2013). American health care as a source of humor. Retrieved May 5, 2016, from http://economix.blogs.nytimes.com/2013/05/10/american-health-care-as-a-source-of-humor/?_r=0

The Scan Foundation (October 2011). *Medicare spending by functional impairment and chronic conditions*. Retrieved May 3, 2016 from http://www.thescanfoundation.org/sites/default/files/1pg_databrief_no22.pdf

Schwartz, M. (2012). The U.S. primary care workforce and graduate medical education policy. *Journal of the American Medical Association*, 308(21), 2252-2253.

Singer, P.A., Martin, D.K., & Kelner, M. (1999). Quality end-of-life care: Patients' perspectives. *Journal of the American Medical Association*, 281(2), 163-168.

Smith, A.K., McCarthy, E., Weber, E., Cenzer, I.S., Boscardin, J., Fisher, J., et al. (2012). Half of older Americans seen in emergency department in last month of life; most admitted to hospital, and many die there. *Health Affairs*, 31(6), 1277-1285.

Smith, S., Brick, A., O'Hara, S., & Normand, C. (2014). Evidence on the cost and cost-effectiveness of palliative care: A literature review. *Palliative Medicine*, 28(2), 130-150.

Temel, J.S., Greer, J.A., Muzikansky, A., Gallagher, E.R., Admane, S., Jackson, V.A., et al. (2010). Early palliative care for patients with metastatic non-small-cell lung cancer. *New England Journal of Medicine*, 363(8), 733-742.

Teno, J.M., Clarridge, B.R., Casey, V., Welch, L.C., Wetle, T., Shield, R., et al. (2004). Family perspectives on end-of-life care at the last place of care. *Journal of the American Medical Association*, 291(1), 88-93.

Teno, J.M., Gozalo, P.L., Bynum, J.P., Leland, N.E., Miller, S.C., Morden, N.E., et al. (2013). Change in end-of-life care for Medicare beneficiaries: Site of death, place of care, and health care transitions in 2000, 2005, and 2009. *Journal of the American Medical Association*, 309(5), 470-477.

Unroe, K.T., Sachs, G.A., Dennis, M.E., Hickman, S.E., Stump, T.E., Tu, W., et al. (2016). Effect of hospice use on costs of care for long-stay nursing home decedents. *Journal of the American Geriatrics Society*, 64(4), 723-730.

U.S. Department of Health and Human Services Office of Inspector General. (2011). Medicare hospices that focus on nursing facility residents. Retrieved from <http://oig.hhs.gov/oei/reports/oei-02-10-00070.pdf>.

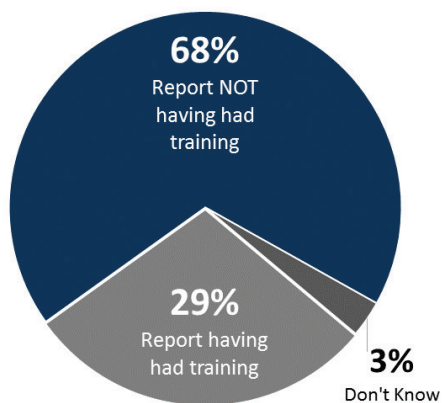
Wang, D., Tsugawa, Y., Figueroa, J., & Jha, A. (2016). Association between the Centers for Medicare and Medicaid Services hospital star rating and patient outcomes. *Journal of the American Medical Association, Internal Medicine*, 176(6), 848-50

Weiss, A., Wier, L., Stocks, C., & Blanchard, J. (2011). Overview of emergency department visits in the United States. Retrieved from <https://www.hcup-us.ahrq.gov/reports/statbriefs/sb174-Emergency-Department-Visits-Overview.pdf>

West, C.P. & Dupras, D.M. (2012). General medicine vs subspecialty career plans among internal medicine residents. *Journal of the American Medical Association*, 308(21), 2241-2247.

Yang, N., Ornstein, K., & Reckrey, J. (2016). Association between symptom burden and time to hospitalization, nursing home placement, and death among the chronically ill homebound. *Journal of Pain Symptom Management*, 52(1), 72-80.

Most physicians report not being trained to discuss end-of-life care (2016)



Before January 1, 2016, Medicare did not reimburse physicians for patient visits to discuss EOL care.

SOURCE: Kaiser Family Foundation, "Medicare Spending at the End of Life: A Snapshot of Beneficiaries Who Died in 2014 and the Cost of Their Care," July 2016. Data from The John A. Harford Foundation "Conversation Stopper: What's Preventing Physicians from Talking with Patients about End-of-Life and Advance Care Planning?" Poll, April 2016.

“As the health care system moves toward integrated financing and delivery models that reward value, hospice and palliative care benefits have often been excluded or carved out of these reforms.”

– HADEN HUSKAMP, PH.D. AND DAVID STEVENSON, PH.D.

Financing Care at the End of Life: Ensuring Access and Quality in an Era of Value-Based Reforms

Haiden Huskamp, Ph.D. and David Stevenson, Ph.D.

The manner in which end-of-life care services are financed is a key determinant of access, quality, and cost of care delivered to individuals as they approach death (Huskamp & Stevenson, 2014). This paper describes current eligibility, coverage, and payment arrangements for end-of-life care services; the challenges these arrangements create for the delivery of high quality care; and key tradeoffs involved in efforts to improve the efficiency and quality of end-of-life care as the U.S. health care system embraces reforms that reward value in service provision.

Background

High Health Care Spending and Individuals Approaching Death

As concerns about rapid growth in health care spending have increased over the past few decades, many have focused on expenditures for individuals approaching death as a key driver of expenditure growth. Although the majority of decedents are among those with the highest spending (e.g., the top 5%) in a given year, the vast majority of the highest spenders are not individuals in the final year of life (Aldridge & Kelley, 2014). For example, only 11% of individuals with the highest health care spending in 2011 were in the final year of life (Aldridge & Kelley, 2014). Almost half of the top spenders (49%) had a discrete high-cost health event (e.g., acute myocardial infarction) in that year, but were not among the highest spenders in the following year (Aldridge & Kelley, 2014). The other 40% had persistently high costs from year to year; this group often had multiple chronic conditions, and those who also had functional limitations were disproportionately represented among the highest cost individuals (Aldridge & Kelley, 2014). Although health expenditures are often high at the end of life, the share of Medicare spending devoted to individuals in their final year has remained

relatively constant for decades (Riley & Lubitz, 2010), and this population should not be singled out as a driver of expenditure growth.

Medicare's Predominance as Payer of End-of-Life Care Services

Medicare is the predominant payer of care for individuals at the end of life, financing services for around 70% of those who die each year in the U.S. This is due to the fact that almost three-quarters (73.3%) of all deaths in 2013 were among those 65 years of age and older, a group with almost universal eligibility for Medicare coverage (Centers for Disease Control and Prevention, 2016). While approximately 13% of total health care spending in the U.S. is devoted to the care of individuals in the last year of life (Aldridge & Kelley, 2014), the share of Medicare spending accounted for by beneficiaries in their final year is twice that size, at 25% (Riley & Lubitz, 2010). Nonetheless, as we note below, non-Medicare covered services (such as long-term services and supports) and family caregiving play substantial roles as well. Reflecting the dominance of Medicare as a payer of end-of-life care services and the fact that other payers often follow Medicare's lead in structuring the financing of care, we focus primarily on Medicare's financing approach.

General Issues with Medicare's Approach to Financing Care

The fee-for-service payment system that is the foundation of reimbursement for the over two-thirds of Medicare beneficiaries enrolled in the traditional Medicare program is an important influence on care received at the end of life by older Americans (Jacobson, Damico, & Gold, 2015). Fee-for-service payment provides incentives to deliver more (and often higher-intensity) care and can lead to fragmentation in financing and service delivery. The predominance of fee-for-service payment in U.S. health care financing is often identified as an important impediment to addressing problems of poor coordination and quality of care, and growing health care expenditures (Schroeder & Frist, 2013).

The traditional Medicare program historically has done little to encourage coordination of care across settings or types of benefits. Medicare has generally used a "silo" approach to coverage and reimbursement, with a separate eligibility and payment system for a given provider type for a specific type of service. This approach ignores interrelationships between providers and the services they deliver and can distort clinical decision-making. Fragmentation and incentives to provide more aggressive care can be particularly harmful for individuals approaching death, contributing to higher rates of hospitalization and intensive procedures at the end of life and care that is misaligned with patient and family

preferences (Barnato, McClellan, Kagay, & Garber, 2004; Kwok et al., 2011; Teno et al., 2013; Wright et al., 2016). Recent demonstrations of integrated financing and service delivery models within the Medicare program hold promise. Yet, as we discuss in more detail below, hospice is carved out from Medicare Advantage (Medicare's managed care program that currently enrolls around 30% of beneficiaries (Jacobson et al., 2015)) and most integrated payment models in Medicare (e.g., Bundled Payments for Care Improvement Initiative; the Duals Financial Alignment Demonstration; and PACE or the Program for All-Inclusive Care for the Elderly). One notable exception is the Medicare Accountable Care Organization (ACO) demonstrations authorized under the Affordable Care Act (ACA).

Medicare and the Financing of End-of-Life Care Services

Medicare covers a broad range of acute and post-acute care services used by individuals with advanced illness, including hospital care, physician services, and post-acute skilled nursing facility care and home health care, with prescription medication coverage available through a separate, voluntary benefit. The primary mechanism for financing palliative and end-of-life care services in the Medicare program (and in most state Medicaid programs and commercial insurance plans, for that matter) is the hospice benefit. Medicare added hospice in 1983 as an alternative to curative care, both to improve the dying experience for terminally ill beneficiaries and to reduce the intensity and cost of health care services at the end of life.

Hospice relies on interdisciplinary care teams with physicians, nurses, home health aides, social workers, counselors, chaplains, therapists and trained volunteers and encompasses a broad array of palliative and supportive services, including expert pain and symptom management, psychosocial and spiritual care, hospice aide and homemaker services, medical equipment and supplies, and bereavement support for families. Based on detailed visit data that report visit type across hospice stays, skilled nursing visits play the most prominent roles at the beginning and end of a hospice stay, while home health aide visits play a relatively more prominent role on other days (Sheingold, Bogasky, & Stearns, 2015). Although data on the cost-effectiveness of hospice are mixed (Gozalo, Plotzke, Mor, Miller, & Teno, 2015; Obermeyer et al., 2014), hospice appears to deliver valuable benefits to recipients, including reduced numbers of hospitalizations, greater attention to emotional and spiritual needs, improved pain management, and greater patient and family satisfaction (Meier, 2011).

From its initial focus on community-dwelling seniors with cancer, the Medicare hospice benefit has grown to reach a much wider range of Americans at the end of life (Table 1).

TABLE 1: The Medicare Hospice Benefit: 1990, 2000, and 2014

	1990¹	2000²	2014²
Number of hospice users	76,500	513,000	1,159,000
Percent of Medicare decedents using hospice	5.5%	22.9%	47.8%
Mean length of hospice stay (days)	67	54	88
Median length of hospice stay (days)	25	17	17
Percent of hospice users with non-cancer diagnoses	16%	49%	71%
Percent of hospice users living in nursing homes	NA	21.7% ⁴	31.1% ⁵
Number of Medicare-certified hospice agencies	806 ³	2,318	4,092
Percent of hospice agencies that are for-profit	14.5% ³	32.6%	63.3%
Total hospice spending	\$309 million	\$2.9 billion	\$15.1 billion
<p>¹ Except where noted, figures for 1990 are from Gage B. Miller S.C., Coppola K., et al. Important questions for hospice in the next century. Washington, DC: DHHS Office of the Assistant Secretary for Planning and Evaluation; 2000.</p> <p>² Except where noted, figures for 2000 and 2014 are from the Medicare Payment Advisory Commission.</p> <p>³ National Hospice and Palliative Care Organization. Facts and Figures: Hospice Care in America.</p> <p>⁴ Miller S.C., Lima J., Gozalo P.L., Mor V. The growth of hospice care in U.S. nursing homes. <i>Journal of the American Geriatrics Society</i> (2010). 58:1481-8. Figure from 1999.</p> <p>⁵ U.S. Office of the Inspector General. Medicare hospices that focus on nursing facility residents. Washington, D.C.: OIG; July 2011. Figure from 2009.</p> <p>NA=not available; dollars are not inflation-adjusted.</p>			

More than two-thirds of hospice users now have non-cancer diagnoses, and around one-third of recipients live in nursing homes, a setting that wasn't even included in the benefit until 1989 (Gozalo et al., 2015; Stevenson & Bramson, 2009). As hospice users have evolved in their prevalent terminal diagnoses, so too has the use of the benefit overall. The average length of use among hospice enrollees has increased considerably in recent years (from 54 to 88 days be-

tween 2000 and 2014), driven by a sizeable minority of very long hospice stays (MedPAC, 2016). The hospice provider market also has expanded and changed markedly as the benefit has grown, transitioning from a relatively small base of locally run non-profit agencies to a much larger sector in which the majority of agencies are run on a for-profit basis (MedPAC, 2016). More than 1.3 million beneficiaries used the Medicare hospice benefit in 2014, including almost half of all Medicare decedents (MedPAC, 2016). Program spending on the benefit was \$15.1 billion in 2014, an amount that was nearly quadruple spending from a decade earlier (MedPAC, 2016).

Despite the apparent comprehensiveness of the benefits described above, Medicare does not cover all services used by individuals as they approach death, with long-term services and supports, such as assistance in performing activities of daily living (such as eating, dressing, and bathing) and instrumental activities of daily living (such as preparing meals, managing medications, and house-keeping), representing one important gap in coverage. Also, like Medicaid and commercial insurers, Medicare does not provide reimbursement for informal caregiving provided by family and friends, which is a key source of support and care for individuals at the end of life. Although hospice explicitly recognizes and provides coverage for bereavement support, the financial, emotional, and physical costs of family caregiving for people at the end of life are still substantial and not well documented. The recent Institute of Medicine report *Dying in America* highlighted these costs and characterized the “growing recognition of and support for the role of caregivers” as a key opportunity to improve end-of-life care (Institute of Medicine, 2014).

Importantly, although palliative care can be introduced at any point in a person’s illness to manage symptoms and maximize quality of life, little explicit coverage of palliative care services is available in Medicare outside of the hospice benefit. In other words, for beneficiaries with advanced illness, Medicare covers acute medical and rehabilitative needs, sometimes with very high out-of-pocket costs due to significant cost-sharing requirements in the Medicare program, but few of the supportive and palliative services that might be needed to remain at home, unless hospice -- which is not a good fit for everyone -- is elected.

Modest pockets of palliative care coverage are available to Medicare beneficiaries. Under the Medicare Prescription Drug Improvement and Modernization Act of 2003, for instance, hospices are eligible to receive a one-time, per beneficiary payment for evaluation and counseling services provided by a hospice physician to a beneficiary who has not elected the hospice benefit and has a prognosis of six months or less. In addition, physicians can receive reimburse-

ment for some palliative care consultation as part of physician services financed by Medicare Part B, although payments for these often time-intensive discussions have historically been poorly reimbursed. However, effective January 1, 2016, the Centers for Medicare and Medicaid Services (CMS) introduced two billing codes for face-to-face advance care planning discussions between patients and physicians or other health care professionals, the impact of which remains to be seen.

Although limited to individuals who are hospitalized, more substantial progress has been made in expanding hospital-based palliative care programs over the last few decades. Many hospitals currently offer palliative care consultation services, despite the lack of reimbursement. Researchers report that the proportion of hospitals with 50 or more beds that have such programs increased from 24% to 67% between 2000 and 2013 (Center to Advance Palliative Care, 2013; Dumanovsky et al., 2016). Some observers predict inpatient palliative care programs are poised to play a more prominent role in the future given the increased role of value-based payment mechanisms and other incentives for successful discharge (e.g., re-admissions penalties) (Cassel, Kerr, Kalman, & Smith, 2015).

How Other Payers Finance End-of-Life Care Services

Medicaid and private insurance plans generally cover a benefit package that is similar to that covered by Medicare and use similar payment methods, often following Medicare's lead with respect to coverage and payment rules across both end-of-life care and other services, as noted above. Private insurance plans vary with respect to covered benefits and cost-sharing requirements. Like Medicare, these plans do not tend to cover long-term services and supports, such as long-term nursing home care, personal care services, and other supportive services. In recent years, use of high-deductible health plans (HDHPs), which require enrollees to pay a large amount out-of-pocket at the beginning of the year before the plan makes any payments and are associated with lower health care utilization in general (Haviland, Eisenberg, Mehrotra, Huckfeldt, & Sood, 2016), has increased rapidly. In 2015, 24% of individuals with employer-sponsored coverage were enrolled in an HDHP, and HDHPs were common among plans offered through the health insurance exchanges for individuals and small groups (Claxton et al., 2015). Exchange plans must cover services in 10 broad categories of "essential health benefits" using the state's specified benchmark plan as the guide for the generosity of coverage. Hospice and palliative care benefits are not included in the 10 required categories, but benchmark plans in all states include hospice as a covered benefit for 2014-2016 (Centers for Medicare and Medicaid Services, 2016).

State Medicaid programs are required to cover a comprehensive set of services that may be used by individuals with advanced illness, such as hospital care, physician services, nursing facility, and home health services, laboratory tests, and X-rays. Medicaid programs can elect to cover additional services, including hospice and prescription drugs. They also offer personal care services and a wide range of home and community-based care services, but for these there may be a waiting list since these services are typically offered under enrollment-capped waivers, not as an entitlement for all Medicaid beneficiaries. Medicaid programs use functional eligibility tests to limit who is eligible for these services, and they limit the “amount, duration, and scope” of benefits to contain costs. The result is substantial variation across states in the services available to Medicaid beneficiaries. Currently, all states and the District of Columbia cover prescription drugs, and all but one (Oklahoma) cover hospice. Thirty-one states cover personal care services statewide (Henry J. Kaiser Family Foundation, 2012), and 47 states cover some home and community-based services (although specific covered services vary) through Section 1915(c) waiver programs, with Arizona, Rhode Island, and Vermont doing so through Section 1115 waivers instead (Eiken, Burwell, Gold, Sredl, & Saucier, 2015).

The Medicaid program plays an important safety net role for people at the end of life, especially older people dually eligible for Medicare and Medicaid who are about 10% of all Medicaid beneficiaries (Henry J. Kaiser Family Foundation, 2016). Based on one recent study using data from the Health and Retirement Study, approximately half of all decedents aged 70 and older with dementia are Medicaid recipients at the time of death, a proportion that is about 20% each for decedents with heart disease and cancer (Amy S. Kelley, McGarry, Gorges, & Skinner, 2015).

The extent to which Medicaid policy shapes end-of-life care for its beneficiaries depends, in part, on individuals’ dual eligible status and their site of residence. For the relatively small number of younger, non-dual Medicaid beneficiaries who die, Medicaid largely determines the manner in which their services are financed and delivered, including the role of Medicaid managed care companies, the availability of community-based supports, and the role of the optional Medicaid hospice benefit. As with other aspects of service delivery, however, end-of-life care financing for services received by dual eligible beneficiaries is more complex. For dual eligible beneficiaries at the end of life, Medicare is the primary payer (i.e., it pays first) for any Medicare covered services, including hospital, outpatient, post-acute, and hospice care. Medicaid pays for Medicare cost-sharing, such as premiums, deductibles, and co-insurance and for any services covered by Medicaid and not Medicare, including -- most prominently -- long-term services and supports.

For duals at the end of life who also have functional limitations, state Medicaid programs' coverage of long-term services and supports can be especially influential in shaping their end-of-life care. The extent to which states cover supportive services in the community dictates to some degree whether low-income seniors with substantial functional impairments die in the community or in nursing homes. Moreover, within the nursing home, the adequacy of Medicaid payment rates affects the overall quality of nursing home care and other care practices that impact residents at the end of life, such as potentially avoidable hospitalizations (Intrator et al., 2007).

Regardless of payer, individuals with advanced illness face high out-of-pocket expenditures in the final years of life, a fact that is exacerbated by gaps in Medicare coverage and the limited reach of Medicaid. For instance, based on the Health and Retirement Study data presented above, the vast majority of older, non-dementia decedents are not enrolled in Medicaid at the time of death, despite their potential need for supportive services beyond what Medicare can provide. In a study of Medicare beneficiaries who died between 2002 and 2008, average out-of-pocket spending in the five years before death was \$38,688, with a 90th percentile of \$89,106 (A. Kelley et al., 2013). The importance of the gap in coverage for long-term services and supports was affirmed in this study, with nursing home costs accounting for half of the out-of-pocket expenditures among those in the top quartile of expenditures (A. Kelley et al., 2013).

Key Issues in Coverage, Payment, Financing and Delivery of Care at the End of Life

Below we describe key issues with coverage and payment for services delivered at the end of life that can impede the provision of high-quality care. We also discuss challenges associated with the provision of high quality end-of-life care in the context of the transformation in the delivery and financing of care taking place throughout the Medicare program and the U.S. health care system as a whole. Because of its prominent role in end-of-life care, our initial focus is on elements of the Medicare hospice benefit; however, we also raise several issues that pertain to ways in which the benefit relates to the other parts of the health care system.

Coverage and Eligibility

There are two primary eligibility criteria for the Medicare hospice benefit: (1) two physicians (one of whom can be employed by the hospice agency) must certify the individual has a prognosis of six months or less to live should the

illness run its natural course; and (2) the beneficiary must agree to forego treatments intended to cure the illness or prolong life. Guided by the physicians' certification, Medicare hospice is administered in benefit periods—for two initial 90-day periods and then an unlimited number of 60-day periods thereafter. It is important to note that the benefit has no capped duration, as long as a patient continues to meet eligibility requirements. Medicare will not cover both hospice and post-acute skilled nursing facility care (SNF) or home health care if delivered concurrently for the same condition.

Initially meant to target hospice use and ensure the benefit was cost neutral, the two primary eligibility requirements can impede timely enrollment in hospice, especially given how the benefit is currently used. Defining hospice eligibility relative to a six-month prognosis standard can be especially difficult for individuals with non-cancer diagnoses (Christakis & Iwashyna, 2000; Sachs, Shega, & Cox-Hayley, 2004), who now comprise the majority of hospice enrollees. Moreover, limiting hospice to individuals who agree to forego curative therapies creates an artificial distinction between potentially life-prolonging and palliative therapies and could impede both enrollment and quality of care (Meier, 2011; Temel et al., 2010). A related point is that among those using hospice before death, around one-quarter enroll five or fewer days before death (MedPAC, 2013a), a period of time most agree is insufficient to convey the full benefits of hospice (Bradley et al., 2004; Iwashyna & Christakis, 1998; A. S. Kelley, Deb, Du, Aldridge Carlson, & Morrison, 2013; Taylor Jr, Ostermann, Van Houtven, Tulskey, & Steinhauser, 2007). Equally troubling is that many short-stay hospice users enroll in the benefit only after a hospitalization, and often after a hospitalization including an ICU stay. One study estimates that 40% of individuals who used hospice for three or fewer days in 2009 had a hospitalization with an ICU stay prior to hospice enrollment (Teno et al., 2013). In other words, even though an increasing number of Medicare beneficiaries are using the hospice benefit, many do so only after receiving high-intensity services.

Created through a provision in the ACA, the Medicare Care Choices Model aims to address part of the hospice eligibility equation and to improve access to high quality end-of-life care. The three-year, budget neutral demonstration offers Medicare beneficiaries who meet the hospice prognosis standard but have not yet enrolled in hospice the option to receive palliative care services from participating hospice agencies while still receiving therapeutic services from other providers. The demonstration began in January 2016 with 140 agencies slated to participate nationwide. Agencies will be paid up to \$400 per month to provide services currently available under the Medicare hospice benefit to beneficiaries with advanced cancers, chronic obstructive pulmonary disease (COPD),

congestive heart failure, or HIV/AIDS. The demonstration does not alter the six-month prognosis standard, but it does offer targeted groups of beneficiaries concurrent access to hospice and therapeutic services for the same underlying condition.

The impact of these changes remains to be seen. However, “grave concerns” already have been expressed by participating hospice agencies that the program’s enrollment criteria are overly narrow (National Hospice and Palliative Care Organization, 2016). As structured, the demonstration leaves out important hospice user groups, such as those with dementia and end-stage renal disease, and includes a range of other enrollment specifications that reportedly limit potential enrollment (e.g., participants must be enrolled in a stand-alone Part D plan). Beyond these restrictions, it also is unclear whether the monthly payments to hospice agencies will be sufficient to spur substantial innovation. And perhaps more fundamentally, the demonstration does not alter the six-month prognosis requirement, leaving this potential barrier to timely hospice access unchanged. Nonetheless, the demonstration reflects a growing consensus that the Medicare hospice benefit needs to evolve in response to changing patient populations and preferences.

Exploration of concurrent care in the context of Medicare hospice was shaped, in part, by evidence of similar innovations in the private sector. Aetna has used a concurrent care model for almost a decade for a subset of its commercial clients. In 2004, Aetna expanded its hospice and palliative care benefits in two key ways: (1) by allowing members to receive curative therapies while enrolled in hospice (i.e., concurrent care); and (2) by requiring a prognosis of 12 or fewer months for hospice eligibility, rather than Medicare’s six-month prognosis (Krakauer, Spettell, Reisman, & Wade, 2009; Spettell et al., 2009).

Although Aetna reports that its approach has been successful (i.e., increasing hospice enrollment, decreasing hospitalizations, and reducing overall costs compared to historical controls (Krakauer et al., 2009; Spettell et al., 2009)), it is not possible to extrapolate the Aetna experience to the current Medicare demonstration, given the different populations that will be enrolled and the distinct design approaches. In particular, as noted above, the Medicare Care Choices demonstration takes a narrower approach and does not address potential barriers to timely hospice enrollment created by the six-month prognosis requirement. Outside of the Aetna program, no other published studies shed light on the expected costs and benefits of concurrent care.

While Medicare is experimenting with models of funding concurrent care for its beneficiaries, Medicaid programs must now finance such care for all their child

beneficiaries. Under the ACA, state Medicaid programs are required to pay for concurrent care for children under age 21 who meet the six-month prognosis criterion. No published studies have assessed the effects of the ACA-related changes for children.

Payment

Despite the transformation in the types of patients who use the Medicare hospice benefit, the providers who deliver hospice, and the settings where hospice services are delivered, the methods used to pay for hospice services have remained largely unchanged since the benefit's inception over 30 years ago. Hospices are paid using one of four rates based on the level of care provided: (1) routine home care, which accounts for nearly 98% of all Medicare hospice days (\$187 per day for days 1-60 of a stay; \$147 for days 61+ in FY16); (2) continuous home care, which is intended to manage a short-term symptom crisis in the home and involves a minimum of eight hours of care per day (\$39.37 per hour, with a maximum daily rate of \$945 in FY16); (3) general inpatient care (GIC) for inpatient care to treat symptoms that cannot be managed in other settings (\$720 per day in FY16); and (4) inpatient respite care, intended to provide a period of respite for a primary caregiver of up to five days (\$167 per day in FY16). These rates, adjusted only to account for differences in local wage rates, are intended to cover all care related to the individual's terminal condition.

The one-size-fits-all approach to reimbursement involving a single per diem payment for all hospice days paid under the routine home care rate can create inefficiencies in service delivery, distort provider decision making, and result in access problems for individuals with high-cost palliative care needs. Longer stays tend to be more profitable under the flat per diem system because they allow hospices to average the generally higher costs of the first and last days of a hospice stay over a larger number of lower-cost "middle" days (Bogasky, Sheingold, & Stearns, 2014; Huskamp, Newhouse, Norcini, & Keating, 2008). The Medicare Payment Advisory Commission has expressed concerns that this one-size-fits-all approach leads some hospices to focus on patients likely to have longer than average stays as a profit maximizing strategy (MedPAC, 2009, 2016). In fact, even after accounting for patient characteristics, for-profit chain and non-chain agencies had longer mean lengths-of-stay (84.5 and 91.2 days, respectively) than other agency types (66.3-72.5 days). Using the same per diem rate for nursing home residents and individuals who reside in the community also leads to inefficiencies, given that average hospice costs are generally lower for nursing home residents (Department of Health and Human Services Office of Inspector General, 1997). Moreover, using a single payment rate across all hospice

patients can also contribute to access problems for individuals with particularly high-cost palliative care needs (Huskamp, Buntin, Wang, & Newhouse, 2001; Lorenz, Asch, Rosenfeld, Liu, & Ettner, 2004). The one-size-fits-all approach is inconsistent with many other Medicare payment systems, which attempt to better align payments with expected costs (e.g., DRGs) or use outlier approaches to compensate providers more for treating particularly high-cost patients, which helps address access problems for these patients.

Section 3132(a) of the ACA called on the Secretary of Health and Human Services to reform Medicare's hospice payment system. Effective January 1, 2016, CMS replaced the flat per diem rate for routine home care days (\$159.34 for FY15) with two rates: a higher rate (\$187.54) for days 1-60 of a stay and a lower rate for all subsequent days (\$145.14). This change was intended to align payments more closely with costs over the course of a hospice stay, making longer stays less profitable. In addition, to encourage hospices to provide more skilled care at the very end of life, CMS began offering a service intensity add-on (SIA) payment for up to four hours of direct patient care delivered by a registered nurse or social worker during a hospice enrollee's last seven days of life. In combination, these provisions represent relatively modest changes in payment, and do not address differences in average costs across settings, barriers to care created by current hospice eligibility standards, or other financing related issues (Stevenson & Huskamp, 2016). No changes were made to the other three hospice payment categories (GIC, continuous home care, and respite), although concerns have been raised that hospice providers, particularly for-profit hospices, are billing for GIC in inappropriate circumstances (Department of Health and Human Services Office of Inspector General, 2016).

Value-Based Payment Reform and End-of-Life Care

As noted above, Medicare, Medicaid, and private payers are increasingly moving toward integrated financing and delivery models in an effort to achieve greater value and improve care coordination (Schroeder & Frist, 2013). Within the Medicare program, Medicare Advantage is a prominent example of the shift away from traditional fee-for-service reimbursement. Medicare pays plans a capitated rate to cover all care, encouraging plans to deliver high-value care. In addition, plans receive "star" ratings based on a range of patient and plan data and began receiving bonus payments based on these quality ratings in 2012. Many other targeted efforts, including the Medicare ACO Demonstration Programs authorized under the Affordable Care Act (i.e., Shared Savings Program, Pioneer ACO program), bundled payment initiatives, and financial alignment

demonstrations for beneficiaries dually eligible for Medicare and Medicaid, also seek to promote models that place greater accountability for cost and quality on payers and large provider organizations.

With caveats that we note below, integrated financing and delivery models have some conceptual appeal for patients with advanced illness at the end of life. If offered among a set of comprehensive benefits, for instance, hospice and palliative care could be integrated at any point in an individual's disease trajectory based on clinical need and not on a specific service benefit's eligibility criteria (e.g., having an expected six-month prognosis and foregoing life extending treatment while enrolled). Moreover, when health plans and providers are paid on a per-person or per-episode basis, payment incentives ostensibly reward efforts to manage chronic disease and minimize unnecessary treatment intensity at the end of life, a prominent challenge of our current system that is noted above.

With the exception of the Medicare ACO Demonstration Programs (which put providers at risk for all Part A and Part B services, including hospice), Medicare's default policy to date has been exclusion of hospice from integrated financing and delivery models. Hospice is not included among the Medicare and Medicaid benefits to be coordinated through CMS's Financial Alignment Initiative, for instance, and none of the Medicare Bundled Payments for Care Improvement Initiative models include hospice and palliative care services. Perhaps most significantly, as we mention above, hospice has always been carved out or excluded from the Medicare Advantage program. When Medicare Advantage members enroll in hospice, fee-for-service Medicare becomes the payer for both hospice care and care unrelated to the terminal condition. The hospice carve-out ensures that Medicare Advantage enrollees have access to the specialized hospice provider of their choice, when they want it. However, the carve-out also lessens Medicare Advantage plans' incentives to bolster their own advanced illness expertise and creates a financial incentive for plans to cede clinical and financial responsibilities for end-of-life care to hospice providers whenever possible since individuals with advanced illness are generally a higher cost population. Eliminating the carve-out would not remove all barriers to timely delivery of hospice and palliative care services; however, it could create opportunities for innovation at a broader scale than the Medicare Care Choices demonstration.

Whether in the context of Medicare Advantage or elsewhere, an important barrier to incorporating end-of-life care into financing and delivery reform is the lack of established quality measures to hold providers accountable for the care they deliver. It is increasingly common for public and private payers to structure contracts with provider incentives to meet specified performance standards; howev-

er, these mechanisms typically have had little emphasis on end-of-life care. The Medicare ACO demonstration programs, for instance, include 33 performance measures in ACO contracts, but none are related to the provision of high-quality end-of-life care (Huskamp & Stevenson, 2014). Similarly, although the National Quality Forum (NQF) recently endorsed a set of quality measures with relevance to palliative and end-of-life care, the Healthcare Effectiveness Data and Information Set (HEDIS) measures used to assess and monitor Medicare Advantage plans historically have not included such measures. Of course, the importance of developing and incorporating end-of-life care quality measures extends beyond integrated financing and delivery models. Despite the fact that one-in-four Americans die in nursing homes, CMS's Nursing Home Compare website and 5-Star Rating System include few measures that have relevance to end-of-life care quality (Teno et al., 2013), a situation that reflects the predominant orientation of nursing home clinical practice and oversight on the maintenance and rehabilitation of physical functioning.

Progress has been made in developing end-of-life care quality measures, as evidenced most prominently by the recent NQF endorsement (Weireter, 2012) and by the ACA required development and proposed public reporting of hospice quality measures. Yet, incorporating these measures into provider contracts and oversight will be essential as health care is shaped increasingly by integrated financing and delivery systems such as Medicare Advantage plans, ACOs, and patient-centered medical homes. In particular, policy development needs to ensure adequate provider networks for patients (e.g., including access to palliative care specialists), suitable quality measurement for oversight, and sufficiently flexible financial incentives to foster coordination of care and mitigate incentives for selection or for stinting on needed care.

Key Challenges and Tensions

We conclude with five challenges and tensions that should be considered in the context of efforts to reform the financing of end-of-life care services and to help ensure high-quality, high-value care moving forward:

- The current approach to financing end-of-life care in the U.S. and its emphasis on hospice offers individuals a well-defined alternative to traditional, curative medicine at the end of life, but it has important trade-offs.
- Defining hospice eligibility relative to a six-month prognosis standard is clinically arbitrary and practically difficult, especially for the majority of hospice users with non-cancer diagnoses.

- Moreover, limiting hospice to those who forgo disease-modifying therapies enforces an artificial distinction between curative and palliative therapy and can impede enrollment and quality of care.
- Although comprehensive in its focus, the Medicare hospice benefit does not cover all the service needs of beneficiaries as they approach death. The lack of coverage for long-term services and supports is perhaps the most prominent coverage gap. The Medicaid program offers low-income seniors a limited safety net of supports, but these gaps still place a substantial burden on beneficiaries and their families.
- A wide range of individuals currently use hospice across different settings of care, but Medicare reimbursement does little to account for this. Per diem payments unadjusted for setting or for patient need are inconsistent with payment methods used for other Medicare-covered services and lead to inefficiencies and access issues for patients with particularly high-cost palliative care needs.

As the health care system moves toward integrated financing and delivery models that reward value, hospice and palliative care benefits have often been excluded or carved out of these reforms. Although this approach offers some protections for beneficiaries, the exclusion of hospice and palliative care benefits from new models of integrated financing and delivery inhibits integration of care and innovation in service delivery.

Given the proliferation of pay-for-performance methods in the health care system overall, end-of-life care stands out for the lack of accountability that providers (including nursing homes, hospitals, home health agencies, and even hospices) face for the quality of care they deliver to individuals as they approach death. Apart from other financing and delivery reforms, progress must be made in identifying and reporting meaningful and valid end-of-life care quality measures.

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References

- Aldridge, M., & Kelley, A. (2014). Appendix E: Epidemiology of serious illness and high utilization of health care. In *Dying in America: Improving quality and honoring individual preferences near the end of life*. Washington, D.C.: National Academies Press.
- Barnato, A.E., McClellan, M.B., Kagay, C.R., & Garber, A.M. (2004). Trends in inpatient treatment intensity among Medicare beneficiaries at the end of life. *Health Services Research*, 39(2), 363-75. <http://doi.org/10.1111/j.1475-6773.2004.00232.x>
- Bogasky, S., Sheingold, S., & Stearns, S. C. (2014). Medicare's hospice benefit: analysis of utilization and resource use. *Medicare & Medicaid Research Review*, 4(2). <http://doi.org/10.5600/mmrr.004.02.b03>
- Bradley, E.H., Prigerson, H., Carlson, M.D., Cherlin, E., Johnson-Hurzeler, R., & Kasl, S. V. (2004). Depression among surviving caregivers: does length of hospice enrollment matter? *American Journal of Psychiatry*, 161(12), 2257-62. <http://doi.org/10.1176/appi.ajp.161.12.2257>
- Cassel, J.B., Kerr, K.M., Kalman, N.S., & Smith, T.J. (2015). The business case for palliative care: Translating research into program development in the U.S. *Journal of Pain and Symptom Management*, 50(6), 741-749. <http://doi.org/10.1016/j.jpainsymman.2015.06.013>
- Center to Advance Palliative Care. (2013). Growth of palliative care in U.S. hospitals: 2013 snapshot. Retrieved April 13, 2016, from https://media.capc.org/filer_public/0d/db/0ddbcbcb-8dc7-449d-aa50-584960f18880/capc-growth-analysis-snapshot-2013.pdf
- Centers for Disease Control and Prevention. (2016). FastStats - Deaths and mortality. Retrieved April 13, 2016, from <http://www.cdc.gov/nchs/faststats/deaths.htm>
- Centers for Medicare and Medicaid Services. (2016). Information on essential health benefits (EHB) benchmark plans - Centers for Medicare & Medicaid Services. Retrieved April 29, 2016, from <https://www.cms.gov/ccio/resources/data-resources/ehb.html>
- Christakis, N.A., & Iwashyna, T.J. (2000). Impact of individual and market factors on the timing of initiation of hospice terminal care. *Medical Care*, 38(5), 528-41.
- Claxton, G., Rae, M., Long, M., Panchal, N., Damico, A., Kenward, K., & Whitmore, H. (2015). Employer health benefits - 2015. Washington, D.C.: Kaiser Family Foundation. Retrieved from <http://files.kff.org/attachment/report-2015-employer-health-benefits-survey>

Department of Health and Human Services Office of Inspector General. (1997). Hospice and nursing home contractual relationships (No. OEI-05-95-00251). Washington, D.C.: U.S. Department of Health and Human Services.

Department of Health and Human Services Office of Inspector General. (2016, March). Hospices inappropriately billed Medicare over \$250 million for general inpatient care. Retrieved April 13, 2016, from <http://oig.hhs.gov/oei/reports/oei-02-10-00491.pdf>

Dumanovsky, T., Augustin, R., Rogers, M., Lettang, K., Meier, D.E., & Morrison, R.S. (2016). The growth of palliative care in U.S. hospitals: A status report. *Journal of Palliative Medicine*, 19(1), 8-15. <http://doi.org/10.1089/jpm.2015.0351>

Eiken, S., Burwell, B., Gold, L., Sredl, K., & Saucier, P. (2015). Medicaid expenditures for section 1915(c) waiver programs in FY 2013. Washington, D.C.: Centers for Medicare and Medicaid Services. Retrieved from <https://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/downloads/1915-expenditures-2013.pdf>

Gozalo, P., Plotzke, M., Mor, V., Miller, S.C., & Teno, J.M. (2015). Changes in Medicare costs with the growth of hospice care in nursing homes. *New England Journal of Medicine*, 372(19), 1823-31. <http://doi.org/10.1056/NEJMsa1408705>

Haviland, A.M., Eisenberg, M.D., Mehrotra, A., Huckfeldt, P.J., & Sood, N. (2016). Do "Consumer-Directed" health plans bend the cost curve over time? *Journal of Health Economics*, 46, 33-51. <http://doi.org/10.1016/j.jhealeco.2016.01.001>

Henry J. Kaiser Family Foundation. (2012). Medicaid benefits: Personal care services. The Henry J. Kaiser Family Foundation. Retrieved April 29, 2016, from <http://kff.org/medicaid/state-indicator/personal-care-services/>

Henry J. Kaiser Family Foundation. (2016). Distribution of Medicaid enrollees by enrollment group. Retrieved from <http://kff.org/medicaid/state-indicator/distribution-of-medic-aid-enrollees-by-enrollment-group/>

Huskamp, H., Buntin, M., Wang, V., & Newhouse, J. (2001). Providing care at the end of life: Do Medicare rules impede good care? *Health Affairs*, 20(3), 204-11.

Huskamp, H., Newhouse, J., Norcini, J., & Keating, N. (2008). Variation in patients' hospice costs. *INQUIRY: The Journal of Health Care Organization, Provision, and Financing*, 45(2), 232-244. http://doi.org/10.5034/inquiryjrn1_45.02.232

Huskamp, H., & Stevenson, D. (2014). Appendix D: Financing care at the end of life and the implications of potential reforms. In *Dying in America: Improving quality and honoring individual preferences near the end of life*. Washington, D.C.: National Academies Press.

Inrator, O., Grabowski, D.C., Zinn, J., Schleinitz, M., Feng, Z., Miller, S., & Mor, V. (2007). Hospitalization of nursing home residents: the effects of states' Medicaid payment and bed-hold policies. *Health Services Research*, 42(4), 1651-1671. <http://doi.org/10.1111/j.1475-6773.2006.00670.x>

IOM (Institute of Medicine). (2014). *Dying in America: Improving quality and honoring individual preferences near the end of life*. Washington, D.C.: The National Academies Press.

Iwashyna, T.J., & Christakis, N.A. (1998). Attitude and self-reported practice regarding hospice referral in a national sample of internists. *Journal of Palliative Medicine*, 1(3), 241-248. <http://doi.org/10.1089/jpm.1998.1.241>

Jacobson, G., Damico, A., & Gold, M. (2015, June 30). Medicare Advantage 2015 spotlight: Enrollment market update. Retrieved from <http://kff.org/medicare/issue-brief/medicare-advantage-2015-spotlight-enrollment-market-update/>

Kelley, A.S., Deb, P., Du, Q., Aldridge Carlson, M.D., & Morrison, R.S. (2013). Hospice enrollment saves money for Medicare and improves care quality across a number of different lengths-of-stay. *Health Affairs*, 32(3), 552-61. <http://doi.org/10.1377/hlthaff.2012.0851>

Kelley, A.S., McGarry, K., Fahle, S., Marshall, S.M., Du, Q., & Skinner, J.S. (2013). Out-of-pocket spending in the last five years of life. *Journal of General Internal Medicine*, 28(2), 304-309. <http://doi.org/10.1007/s11606-012-2199-x>

Kelley, A.S., McGarry, K., Gorges, R., & Skinner, J.S. (2015). The burden of health care costs for patients with dementia in the last 5 years of life. *Annals of Internal Medicine*, 163(10), 729-736. <http://doi.org/10.7326/M15-0381>

Krakauer, R., Spettell, C.M., Reisman, L., & Wade, M.J. (2009). Opportunities to improve the quality of care for advanced illness. *Health Affairs*, 28(5), 1357-9. <http://doi.org/10.1377/hlthaff.28.5.1357>

Kwok, A.C., Semel, M.E., Lipsitz, S.R., Bader, A.M., Barnato, A.E., Gawande, A.A., & Jha, A.K. (2011). The intensity and variation of surgical care at the end of life: a retrospective cohort study. *Lancet*, 378(9800), 1408-13. [http://doi.org/10.1016/S0140-6736\(11\)61268-3](http://doi.org/10.1016/S0140-6736(11)61268-3)

Lorenz, K.A., Asch, S.M., Rosenfeld, K.E., Liu, H., & Ettner, S.L. (2004). Hospice admission practices: Where does hospice fit in the continuum of care? *Journal of the American Geriatrics Society*, 52(5), 725-730. <http://doi.org/10.1111/j.1532-5415.2004.52209.x>

MedPAC. (2009). Reforming Medicare's hospice benefit. In *Report to the Congress: Medicare payment policy* (March 2009) (pp. 347-376). Washington, D.C.: The Medicare Payment Advisory Commission.

MedPAC. (2013a). Hospice services. In *Report to the Congress: Medicare payment policy* (March 2013) (pp. 259-284). Washington, D.C.: The Medicare Payment Advisory Commission.

MedPAC. (2013b). Medicare and the health care delivery system. Washington, D.C.: The Medicare Payment Advisory Commission.

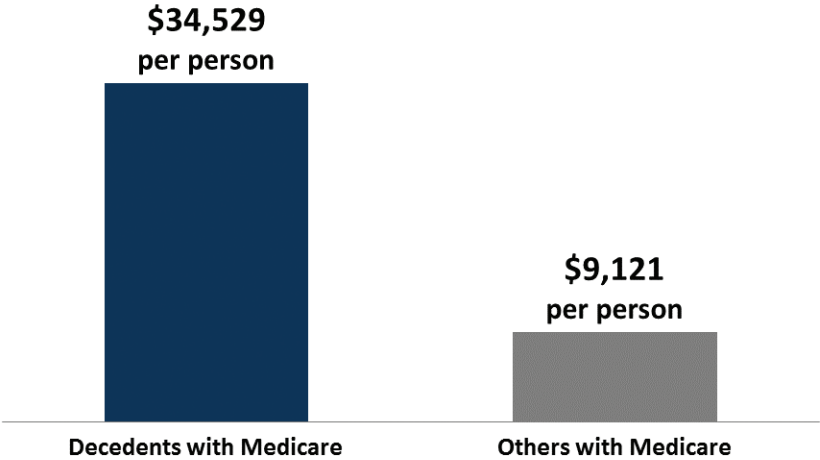
MedPAC. (2016). Hospice services. In *Report to the Congress: Medicare payment policy* (March 2016) (pp. 299-323). Washington, D.C.: The Medicare Payment Advisory Commission.

Meier, D.E. (2011). Increased access to palliative care and hospice services: Opportunities to improve value in health care. *Milbank Quarterly*, 89(3), 343-80. <http://doi.org/10.1111/j.1468-0009.2011.00632.x>

National Hospice and Palliative Care Organization. (2016, March 7). Letter to Patrick Conway, MD, Centers for Medicare and Medicaid Services. Retrieved from http://hospice-actionnetwork.org/linked_documents/get_informed/policy_resources/MCCM_letter_Conway_March2016.pdf

- Obermeyer, Z., Makar, M., Abujaber, S., Dominici, F., Block, S., & Cutler, D.M. (2014). Association between the Medicare hospice benefit and health care utilization and costs for patients with poor-prognosis cancer. *Journal of the American Medical Association*, 312(18), 1888-96. <http://doi.org/10.1001/jama.2014.14950>
- Riley, G.F., & Lubitz, J.D. (2010). Long-term trends in Medicare payments in the last year of life. *Health Services Research*, 45(2), 565-576. <http://doi.org/10.1111/j.1475-6773.2010.01082.x>
- Sachs, G.A., Shega, J.W., & Cox-Hayley, D. (2004). Barriers to excellent end-of-life care for patients with dementia. *Journal of General Internal Medicine*, 19(10), 1057-1063. <http://doi.org/10.1111/j.1525-1497.2004.30329.x>
- Schroeder, S.A., & Frist, W. (2013). Phasing out fee-for-service payment. *New England Journal of Medicine*, 368(21), 2029-2032. <http://doi.org/10.1056/NEJMSb1302322>
- Sheingold, S., Bogasky, S., & Stearns, S.C. (2015). Medicare's hospice benefit: Revising the payment system to better reflect visit intensity. Washington, DC: Assistant Secretary for Planning and Evaluation. Retrieved from <https://aspe.hhs.gov/basic-report/medicares-hospice-benefit-revising-payment-system-better-reflect-visit-intensity>
- Spettell, C.M., Rawlins, W.S., Krakauer, R., Fernandes, J., Breton, M.E., Gowdy, W., ... Brennan, T.A. (2009). A comprehensive case management program to improve palliative care. *Journal of Palliative Medicine*, 12(9), 827-32. <http://doi.org/10.1089/jpm.2009.0089>
- Stevenson, D., & Bramson, J. (2009). Hospice care in the nursing home setting: a review of the literature. *Journal of Pain Symptom Management*, 38(3), 440-51.
- Stevenson, D., & Huskamp, H. (2016, January 4). Hospice payment reforms are a modest step forward, but more changes are needed. Retrieved April 13, 2016, from <http://healthaffairs.org/blog/2016/01/04/hospice-payment-reforms-are-a-modest-step-forward-but-more-changes-are-needed/>
- Taylor Jr, D.H., Ostermann, J., Van Houtven, C.H., Tulsy, J.A., & Steinhauser, K. (2007). What length of hospice use maximizes reduction in medical expenditures near death in the U.S. Medicare program? *Social Science & Medicine*, 65(7), 1466-1478. <http://doi.org/10.1016/j.socscimed.2007.05.028>
- Temel, J.S., Greer, J.A., Muzikansky, A., Gallagher, E.R., Admane, S., Jackson, V.A., ... Lynch, T.J. (2010). Early palliative care for patients with metastatic non-small-cell lung cancer. *New England Journal of Medicine*, 363(8), 733-42. <http://doi.org/10.1056/NEJMoa1000678>
- Teno, J.M., Gozalo, P.L., Bynum, J.P., Leland, N.E., Miller, S.C., Morden, N.E., ... Mor, V. (2013). Change in end-of-life care for Medicare beneficiaries: site of death, place of care, and health care transitions in 2000, 2005, and 2009. *Journal of the American Medical Association*, 309(5), 470-7. <http://doi.org/10.1001/jama.2012.207624>
- Weireter, E. (2012, February 14). NQF: NQF endorses palliative and end-of-life care measures. Retrieved April 14, 2016, from http://www.qualityforum.org/News_And_Resources/Press_Releases/2012/NQF_Endorses_Palliative_and_End-of-Life_Care_Measures.aspx
- Wright, A.A., Keating, N.L., Ayanian, J.Z., Chrischilles, E.A., Kahn, K.L., Ritchie, C.S., ... Landrum, M.B. (2016). Family perspectives on aggressive cancer care near the end of life. *Journal of the American Medical Association*, 315(3), 284-292. <http://doi.org/10.1001/jama.2015.18604>

Medicare spending was higher for people at the end of life in 2014



NOTE: Excludes beneficiaries in Medicare Advantage.
SOURCE: Kaiser Family Foundation, "Medicare Spending at the End of Life: A Snapshot of Beneficiaries Who Died in 2014 and the Cost of Their Care," July 2016. Data from Kaiser Family Foundation analysis of 5% percent sample of Medicare claims from CMS' Chronic Conditions Data Warehouse (CCW), 2014.

“Taking a systems approach requires a reorientation of our ethical framework from one focused almost exclusively on individual rights and a “thin” notion of autonomy to a more relational framework that . . . makes commitments to families as well as patients, and aims to develop home and community-based care that supports the patient’s and family’s social, emotional and logistical needs.”

– MILDRED Z. SOLOMON, ED.D.

Doing Right By the Seriously Ill: Ethical Norms for Care Near the End of Life

Mildred Z. Solomon, Ed.D.

We know the dance moves. You agree to become the patient, and I, the clinician, agree to fix you, whatever the improbability, the misery, the damage, or the cost.

~ Atul Gawande, *Being Mortal*

In his 2014 best seller *Being Mortal*, surgeon Atul Gawande points out that we are on a social learning curve, in which we are “rejecting the institutionalized version of aging and death,” characteristic of our time, but have “not yet established our new norm (193).” The purpose of this paper is to articulate the principles that should guide us as we build new systems of care for people near the end of life. More specifically, the paper asks: Why do we need ethical norms near the end of life? What are the norms already articulated in U.S. law and ethical guidelines for decision making in the last phase of life? Why have these guidelines failed to produce the results people want? What other ethical issues must we now address?

Why Do We Need Ethical Norms Near the End of Life?

There was a time, roughly before the mid-20th century, when death was out of our hands. In the United States, people died from tuberculosis and other infections that are now treatable, and from contagious diseases now largely controlled through vaccination and other public health measures. Most of us now live much longer, but with chronic, progressive conditions, such as heart disease, kidney disease, cancer, or diabetes.

In the 1950s and 1960s, new life-sustaining technologies, such as ventilators and dialysis machines, emerged. These technologies are deeply beneficial when they can restore functioning and return people to a quality of life they deem acceptable. However, they have also been called “half-way technologies,” because often they cannot restore people to a level of health they value and can impose burdens and indignities that some may want and others may wish to avoid.

In hospitals and nursing homes in developed countries, the timing and circumstances of death are now largely in human hands. Mere mortals must decide when a medical or surgical intervention is more likely to bring great relief or added misery. There are problems of overuse of non-beneficial treatments, underuse of beneficial treatments, racial disparities in pain and symptom management and in rates of referral to specialist care. Medical costs now contribute to a significant proportion of bankruptcy filings (Himmelstein et al., 2009), and many family caregivers sacrifice greatly, both financially and in terms of disruptions in their own life plans, to care for their loved ones (Levine, 2006). Many elders are socially isolated, and in some cases, virtually abandoned. While many nursing homes provide outstanding care, too many provide inadequate social interaction and too little personal freedom.

What Is Ethics and How Can It Help?

Ethics is a field of study that aims to figure out what the right thing is to do. It offers ethical guideposts and analytic methods to help individuals make decisions about their own behavior as well as discern their duties and obligations toward others. Ethics also helps citizens, organizational leaders and policy makers determine optimal policies and practices for their institutions and communities. Ethics is not about imposing a single morality on all. Rather, it helps us articulate the ways in which different choices reflect different values, so people can make decisions in line with the values they most prize.

Bioethics, the subfield of ethics that focuses on ethical questions arising in health care, public health and the life sciences, has tended to rely upon a small set of principles to shape public policy: respect for persons, which in the United States we express as a commitment to self-determination, also called autonomy; non-maleficence (do no harm); beneficence (attending to the welfare of the patient); and justice (equal opportunities for health and fair access to health care). These are summarized in Figure 1.

Enumerating ethical principles takes us only so far. Principles themselves are often in conflict with one another. Commonly there is a clash, for example, between self-determination and beneficence. Imagine someone who has prepared clear instructions that if she develops dementia she does not want to be sustained by medical interventions. What if, when she does become demented, she seems to be enjoying her life? Should her earlier directive be honored as an expression of self-determination or disregarded due to the importance of beneficence? (Dresser, 1986; Dresser, 2014)?

FIGURE 1: Ethical Principles to Guide Care Near the End of Life

- Autonomy (patient self-determination)
- Non-maleficence (do no harm)
- Beneficence (promote wellbeing)
- Justice (fairness)

Autonomy and justice also often clash, due to the tension between the desire to maximize personal choice and the desire to allocate resources in ways that provide greater utility to the population as a whole. An example of an autonomy-justice tension is when a patient requests a marginally beneficial drug that is extremely costly and may offer at best the possibility of a few weeks or months of extra survival time. Based on justice arguments, some health systems have decided to remove very expensive and marginally beneficial chemotherapeutic agents from their formulary (Fojo & Grady, 2009), payers are developing hierarchies of drug regimens to promote the use of less expensive drug choices (Lowell Schnipper, personal communication April 2016), and specialty societies are calling for price reductions (Experts in Chronic Myeloid Leukemia, 2013). The clash between autonomy and justice often plays out in the context of insurance -- whether public or private -- in which resources provided to one person impose costs (in the form of higher premiums or taxes) on others.

Decisions ultimately rest on more than the simple invocation of principles. Narrative ethics emphasizes the importance of coming to understand the patient's story and the perspectives that key people in that story hold (Montello, 2014). Virtue ethics examines the qualities to which persons of high moral character should aspire and asks what our duties and obligations should be in various morally salient situations (MacIntyre, 1981). Feminist ethics focuses on the power relationships between parties as well as the importance of an ethic of care, which should complement the principle of justice (Held, 2007). All of these approaches -- and others -- offer helpful insights relevant to improving end-of-life care.

What Norms are Already Articulated in U.S. Law and Ethical Guidelines?

In 1976 Karen Ann Quinlan's picture appeared on the cover of Newsweek. Her parents believed she would not want to be maintained in an irreversible coma, but her doctors feared that withdrawing the ventilator would constitute killing

and sought a court opinion (in re Quinlan, 1976). Since then, there have been more than one hundred court cases, other legal developments, and the creation of prominent national ethics guidelines (Berlinger, Jennings & Wolf, 2013; Wolf, Berlinger & Jennings, 2015; President's Commission, 1983; The Hastings Center, 1987). Together, these embody an ethical and legal framework for making treatment decisions that involve the use, or forgoing, of life-sustaining technologies. Highlights of this consensus framework are presented in Figure 2.

FIGURE 2: Treatment Decisions at the Bedside: A Broad Consensus on Ethical Norms

- Competent patients can choose to forgo treatments.
- Families and designated surrogates can decide on behalf of incapacitated patients (some states require more stringent criteria than others).
- While patients have primary authority, this right is not absolute. Shared decision making among patients (families, if patients are incapacitated) and physicians is optimal.
- Forgoing treatments (both withholding and withdrawing) is not the same as assisting suicide.
- All types of life support can be withheld or withdrawn.
- The key is to assess the relative burdens and benefits of the proposed decision, as the patient would perceive them.
- Patient authority to refuse interventions is based on the right to self-determination.
- This right is one of refusal. It is not a right to receive anything the patient wants.
- Physicians have the authority to decline the provision of ineffective treatment.
- Withdrawing a life-sustaining technology is not the same as providing a prescription for lethal medications intended to hasten death.

Adapted from Berlinger, Jennings and Wolf (2013). *The Hastings Center Guidelines for Decisions on Life-Sustaining Treatment and Care Near the End of Life*, second edition and *The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Deciding to Forego Life-Sustaining Treatment: Ethical, Medical and Legal Issues in Treatment Decisions*, 1983

The central guiding principle of the United States framework for treatment decision making near the end of life has been a patient's right to self-determination. This principle ensures that two patients, whose medical conditions are virtually identical, have the right to make very different treatment choices. Based on their values, goals or preferences, one person might choose to continue a life-sustaining intervention while another chooses to discontinue it. This right extends to all kinds of interventions: from ventilators to chemotherapeutic agents, from artificial nutrition and hydration to antibiotics (Cruzan v. Director, 1990). The role of clinicians is to help guide that decision making process, clarify choices and the potential consequences of different treatment options, help the patient anticipate the likely trajectories their illness might take, offer but not impose recommendations, and support the patient and family as they consider their options (Berlinger, Jennings & Wolf, 2013).

The right of refusal extends to patients who have lost decisional capacity. For a surrogate decision maker, the question is not "What do you think we should do?" but rather "What would your loved one have wanted?" In cases where it is impossible to know what the incapacitated patient would have wanted, current guidelines ask clinicians and families to use a "best interests" standard. This standard asks what reasonable people are likely to want in such circumstances. In all instances, the goal is to focus surrogate decision makers on the patient's welfare (Berlinger, Jennings & Wolf, 2013).

It is important to underscore that a patient's right to forego treatment is a right of refusal. It is not a right to demand and receive treatments that are ineffective.

Self-Determination Through Advance Directives and Advance Care Planning

Federal and state law and ethics guidelines authorize the use of advance directives, such as durable powers of attorney for health care (also known as proxy directives) and treatment directives (also known as living wills) as a means for effectuating the rights of incapacitated persons. Another treatment directive is the Physician Orders for Life-Sustaining Treatments (POLST) or Medical Orders for Life-Sustaining Treatments (MOLST), which is used to ensure that medical orders are "portable" across settings, particularly when 911 is called for end-stage patients who do not want cardiopulmonary resuscitation (CPR).

Despite decades promoting advance directives, only about a quarter of the adult American population has completed them (Rao, 2014). African-Americans and Hispanics are least likely to complete advance directives (Koss, 2016; Song, 2016). One reason may be that health care providers are less likely to have end-

of-life discussions with African-American and Hispanic patients, particularly in nursing homes (Rich et al., 2009). However, for reasons that are not completely clear, blacks and Latinos are also less likely to consider themselves terminally ill and more likely to want intensive interventions, even if they increase suffering or offer minimal therapeutic benefit (Smith, McCarthy, Paulk et al., 2008).

Moreover, simply completing forms and designating a surrogate decision maker does not provide either the family or the health care team sufficient information to make decisions (Fisch, 2015; Winter et al., 2010). Given the limitations of advance directives, emphasis is now placed on advance care planning, a process that occurs over time through multiple conversations.

One of the most significant recent accomplishments is the 2015 decision by the Centers for Medicare and Medicaid Services (CMS) to reimburse physicians for holding advance care planning conversations with patients (CMS, 2015; Solomon and Berlinger, 2015). To achieve its promise, health care systems and medical specialty societies need to adequately prepare clinicians to hold these conversations and must develop mechanisms to ensure the conversations occur.

Advance care planning is primarily a means for ensuring that the patient's wishes will be followed. But it can also reduce emotional harm to surrogates. When asked to make decisions for incapacitated loved ones, without knowledge of what their loved one would have wanted, one-third of surrogates experience serious, sometimes long-lasting guilt, depression and stress. Those effects are mitigated when surrogates know what their loved ones would have wanted (Wendler & Rid, 2011).

An Unsettled Area: Physician Aid-in-Dying (PAD) or Physician Assisted Suicide (PAS)

Many people wishing to have control over the timing and circumstances of their death are not dependent on life-sustaining technologies that can be withdrawn. Thus, the existing right to refuse unwanted treatment does not provide them with a way to die under their own control. The most highly publicized controversy in ethical norms for end-of-life decision making pertains to physician aid-in-dying (PAD), also called physician assisted suicide (PAS). This area of controversy stands in contrast to the norms for refusing care, where there is significant legal and ethical consensus.

PAD is now legal in five states: Oregon, Washington, California, Montana and Vermont, and is under review in the courts in New Mexico. In all these places,

a physician writes a prescription for a lethal medication, which the person self-administers. Persons receiving such a prescription must have a six-month terminal prognosis agreed upon by two physicians, decisional capacity, and not be depressed.

Proponents of legalization believe that a decision to die in this manner is morally equivalent to withdrawing a ventilator, or other life-sustaining technology, and that keeping PAD illegal is an impediment to self-determination. They prefer the term “physician aid-in-dying,” to distinguish it from suicide.

Some opponents have religious objections, most often expressed in terms of the sanctity of life and a conviction that only God has the authority to end life (Pew Resource Center). Other opponents are concerned it may lead to changing social norms, in which there might emerge an expectation, by the patients themselves or by others, that seriously ill patients should end their lives so as not to become a burden on others. There is also concern that PAD might become an expedient way to reduce costs for families, health systems, communities or the nation. Some are concerned that legalization will lead to discrimination against vulnerable populations, such as the poor or the disabled. Physicians have been divided in their views, with many in support, but many also arguing that physicians should never kill or assist with killing (Kane, 2014).

Most states require that physicians report the prescriptions they write, pharmacists report the ones they fill, and in some states there are monitoring programs that track statistics on use. The Vermont law calls for monitoring only during the first three years after the law’s enactment (Agency of Human Services, 2013). Vermont’s legislators justified the sunset of their monitoring program on the claim that it would be an unnecessary invasion of privacy. Others, such as this author, believe that if PAD is going to be legalized, the state should monitor its use to ensure it is implemented in ethically sound ways.

PAD has been extensively studied in Oregon. The overwhelming majority of people who have used it there are 65 or older, educated, and white. More than 90% were enrolled in hospice, died at home, and cited a “decreased ability to participate in enjoyable activities” and the “loss of autonomy” as significant factors in their decisions (Oregon Health Authority, 2016).

PAD provisions in the United States exclude people who lack decisional capacity, such as people with dementia. Recently, however, this exclusion has been criticized as unfair (Menzel and Steinbock, 2013). Some have argued that people not wishing to live with dementia should be able to develop an advance

directive asking for such assistance with dying should they become demented. Under current laws, such third-party assistance to someone without decisional capacity would be defined as euthanasia, which is illegal in the United States. However, interest in advance directives for assistance with dying may grow as researchers develop reliable biomarkers and tests that identify a person's risk of developing Alzheimer's years before there are symptoms. It is hard to predict how such tests, if widely available, will impact personal wellbeing, attention to end-of-life planning, public demands for better community care for the incapacitated, and interest in advance directives. Regarding the latter, some people have anticipated that if people can reliably identify their risk for Alzheimer's they may wish, while still cognitively capacitated, to develop advance directives requesting euthanasia when they have lost cognitive capacities, or they may opt for PAD before dementia sets in. This would likely mean that they would be asking for PAD well before they had a six-month terminal prognosis, which currently is a requirement.

Despite the broad discussion of PAD in the media and its legalization in a number of states, the reality is that very few people have opted for PAD. It should not be mistaken as the primary way of improving end-of-life care, but only as one option, which only a relatively small proportion of people are likely to adopt.

Why Have These Ethical Guidelines Failed to Produce the Results People Want?

The existing ethics framework in the United States is built on the ethical principle of autonomy and promotes personal choice. It represents an important first step, one that was needed as our society grappled with bedside decision quandaries. However, there are major limitations. Current experience with the limitations of informed consent, the persistence of unnecessary harms, and well-documented disparities in end-of-life care suggest that placing autonomy as the primary ethical value has not generated the care system people desire.

Consent is Not Yet Truly Informed

The emphasis on autonomy has not achieved its goal of ensuring truly informed choice. A compelling ethnography of hospitalized deaths (Kaufman, 2006) and an analysis of the U.S. health care system by the same author (Kaufman, 2015) describe how patients and families (and sometimes doctors) "actually do not *decide* [author's emphasis] about treatments, so much as they yield to procedures."

Patients today are treated by specialists who are experts in specific organ systems and their related life-sustaining treatments. When doctors offer such treatments, patients and families often believe the treatments can restore health, even though the clinician may only be focusing on a particular, short-term goal. For example, it is frequently the case that extended rounds of chemotherapy result in tumor shrinkage, but do not extend survival (Prasad, 2015). Sometimes interventions will help; other times they will only increase suffering. Too often no one is helping the family consider the trade-offs they are willing to make or even indicating that there are trade-offs (Solomon, 1993). Thus, inadequate advance care planning and the pull of the technological imperative have left elders and their family members without guidance.

Patients Experience Unnecessary Harms and Neglect

Many interventions that patients “yield to,” and sometimes demand, are not evidence-based, do not meet patients’ needs, and introduce harms. These harms represent ethical gaps in our moral commitments to non-maleficence, the relief of suffering, and the promotion of wellbeing (beneficence).

For example, CPR and dialysis are offered to patients even when they are likely to be ineffective and burdensome (Blinderman et al., 2012; Schmidt & Moss, 2014). Feeding tubes for the delivery of artificial nutrition and hydration continue to be inserted in patients with aspiration pneumonia despite a large literature demonstrating their ineffectiveness in preventing such pneumonias (Teno, Mitchell, Kuo et al., 2011) and the reality that travel to the hospital for insertion of such tubes can increase agitation and confusion (Unroe and Meier, 2013a).

Although palliative care services have been established in many hospitals across the nation, too many patients still experience unacceptable levels of pain and discomfort and receive inadequate attention to preventing or ameliorating their disabilities (IOM Committee on Approaching Death, 2014). Moreover, admission to intensive care units has climbed to a rate that far exceeds the proportion of patients likely to be benefiting from the ICU (Teno, Gozalo, Bynum et al., 2013). Perhaps most importantly, outside of acute care settings millions of frail elders and those with chronic, ultimately fatal conditions are left isolated in their homes or in suboptimal nursing homes, without adequate social, logistical or disease management supports that would postpone their decline and enhance their quality of life (Lynn, 2004; Gillick, 2006; IOM Committee on Approaching Death, 2015).

Unfair Access and Health Care Disparities

De facto reliance on ability-to-pay and market forces creates unjust distributions of health goods. The high cost of drugs, for example, causes some people to skimp on medications to pay other essential household costs, raising justice concerns, because people with fewer financial means will have less access than those with more resources. Medical costs -- even for those with health insurance -- are a major contributor to personal bankruptcy in the United States (Himmelfest 2009). The high cost of deductibles, co-pays and medicines account for the bulk of expenses, often making families choose between the care of an elder and a college education for a son or daughter. Many thoughtful people do not believe that an enlightened society should apportion access to essential medicines and treatments by ability to pay.

Justice (and non-maleficence) concerns also arise in the context of racial and ethnic health disparities. Not all disparities are injustices (Powers and Faden, 2003). For example, a disparity in health outcomes may arise because groups hold different beliefs and preferences, which may predispose them to behaviors that bring better or worse outcomes. But when race and ethnicity are associated with differential access to care, lower-quality care, and lower rates of referral to specialty care, justice concerns arise.

African-Americans and Hispanics are more likely to have their pain undertreated or untreated than white patients. Causes include both patient factors, such as heightened stoicism and reluctance to report pain, and provider factors, such as lower rates of referral to pain specialists. Pharmacists in poor minority communities are also less likely to have inventories of opioid analgesics (Cintron & Morrison, 2006).

There is also a preponderance of evidence that African-Americans are referred for specialty care far less often than European-Americans (IOM Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care, 2003). Ayanian et al. (2004) demonstrated that black patients with end-stage renal disease were less likely to be referred for work-ups that would evaluate their suitability for kidney transplants than whites. Schulman et al. (1999) showed that African-Americans, particularly black women, were less likely to be referred for cardiac catheterization, when compared with white counterparts with the same medical histories. There are literally hundreds of studies documenting racial disparities in access and referral to specialty care of all kinds (Geiger et al., 2003). Dementia care is going to place huge financial burdens on all families but particularly on African-Americans, those with less than a high school education, and unmarried or widowed women (Kelley, McGarry, Gorges & Skinner, 2016).

What Other Ethical Issues Must We Now Address?

Focusing primarily on individual decision making about medical interventions in the hospital puts the focus on whether to use or forego a particular life-prolonging technology, rather than on building a system of care that attends to the needs of those at the end of life and attempts to alleviate family burdens. The second edition of *The Hastings Center Guidelines* (Berlinger, Jennings & Wolf, 2013) called for a transition from a focus solely on bedside decisions made by individual patients to a more family-centered systems approach, as did the 2015 report, *Dying in America*. In that report, the Institute of Medicine, now called the National Academy of Medicine, called for “a major reorientation of Medicare and Medicaid,” which should “reallocate funding away from preventable or unwanted acute/specialist/emergency care to support more appropriate services...reducing the financial incentives that drive reliance on the riskiest, least suitable and most costly care settings” (IOM Committee on Approaching Death, 2014, pages 266-267). Most recently, insights from research on patient safety and quality improvement have revealed the necessity of tackling improvements to end-of-life care as systemic reforms, rather than relying on patients and families to discern and make good choices in a flawed system (Wolf, Berlinger & Jennings, 2015).

Taking a systems approach requires a reorientation of our ethical framework from one focused almost exclusively on individual rights and a “thin” notion of autonomy to a more relational framework that emphasizes the degree to which persons are embedded in families and dependent on a web of interrelationships. A relational ethic continues to protect patients’ rights to choose their medical treatments, but offers a much richer conception of autonomy, which recognizes that frail and dying patients also need care, love and attentiveness, and their families need respect and support (Jennings, 2014). Thus, a relational ethics framework makes commitments to families as well as patients, and aims to develop home and community-based care that supports the patient’s and family’s social, emotional and logistical needs (Berlinger, Jennings & Wolf, 2013; Committee on Approaching Death, 2014; Jennings, 2014; Browning & Solomon, 2006; Fins, 2006; Lynn, 2004; Meier, Isaacs & Hughes, 2010; Morrissey, 2011 & Solomon, 2014).

Both palliative care and the hospice model of care were built on a relational ethic, but neither can on their own drive the systems level changes that are necessary. First, both palliative care and hospice are dependent upon referrals, which often come very late and for far too few people. Second, the palliative care workforce is not nearly large enough and never will be. Palliative specialists

themselves are now calling for a much larger group of clinicians to be trained to deliver “primary” or “generalist” palliative care, with appropriate specialist back-up (Quill & Abernethy, 2013; Schenker & Arnold, 2015). Hospice care is limited to those with a six-month prognosis, a criterion many have criticized, but that remains in place today. Further, a person may wish to opt for life-saving interventions or skilled nursing that are not available, or more difficult to access, through hospice, and hospice is only available to those who have someone in their home to assist them.

But the most fundamental reason that palliative care and hospice will not be sufficient is that we need to drive upstream changes -- prior to hospitalization or hospice -- that will better support the social and the medical needs of the elderly, so that they can live for as long as possible in their own homes or in assisted living with the greatest possible dignity, control and emotional support. This is a goal that a just society should seek to offer, and it means that the underlying relational ethic embodied in hospice and palliative care needs to find expression in other, complementary forms of care and community support.

What Kinds of Care Systems Would a More Relational Ethic Build?

For some time, we have known that aging persons fall into three groups: elders who are robust and may only need small modifications to what Medicare already provides, such as hearing aids to improve quality of life; those who are actively dying, for whom hospice is an appropriate pathway; and a large middle group with chronic, progressive conditions that will worsen with time, creating considerable disability before death (Gillick, 2006). It is this large, latter group that needs our nation’s attention.

To improve what we have been calling care near the end of life, we must design a continuum of care that supports aging people with chronic, progressive conditions and increasing frailty. Indeed, designing for end of life has not worked and is proving to be an unhelpful paradigm. First, the prognostics are too uncertain; we don’t know for sure when death is imminent or even whether one is actually near the end of life. Second, our own psychology directs us away from embracing death and people understandably resist such labels. Third, the needs people have can only be met by a relational ethic—one that will help families care for their loved ones at home, support solitary elders in their homes for as long as possible, and redesign nursing homes so they are places of greater dignity. Real breakthroughs in how people nearing the end of life are cared for will come, in this author’s view and others, by addressing how well we support the ways the elderly live.

Holistic Care that Helps People with Chronic Conditions and Frailty Stay at Home

Persons with chronic, progressive illnesses are not a unitary group. Lynn (2004) pointed out that people with advanced cancer follow a relatively stable, high level of functioning that drops off sharply in the weeks before death. For people with diseases of major organ systems, the trajectory looks more like a jagged line, featuring acute, potentially fatal episodes, with intensifying interventions between periods of relative stability. A third group is characterized by increasing frailty and cognitive decline due to dementia or stroke, exhibiting a trajectory best described as “dwindling away.”

Experts have proposed that our systems of care be redesigned to meet the distinctive patient and family needs of these very different trajectories and help people stay in their homes for as long as possible. Instead of responding to a disease category, pathways of coordinated care could be developed for people who fall within these broad trajectories or “condition types” (Lynn, 2004; Gillick, 2006; Jennings, 2014).

Excellent models exist, and a distinctive feature is that they address both social and medical needs. For example, although it is not expressly an end-of-life program, The Program for All-inclusive Care of the Elderly (PACE) ensures access for the poor to medical care and social supports at home and within the local community. It has demonstrated that a more comprehensive, social and relational model of care can reduce hospitalizations and ensure longer periods of wellbeing at home (Petigara & Anderson, 2009). However, it has been slow to replicate, in part because recruitment into the program has lagged (IOM Committee on Approaching Death, 2014). As part of a comprehensive look at how to support persons with chronic, progressive conditions at home for as long as possible, we should study what has worked in the PACE program and what has limited its recruitment. Other programs should also be identified and evaluated to generate new ideas for ways to feasibly support elders at home.

More Respectful and Supportive Long-Term Care Arrangements

Even as we improve ways to help people stay in their homes, there often comes a time when people need nursing homes. Here, too, there has been promising innovation. Ethically sound facilities encourage greater independence and personal control so that people can keep as much of their identity intact as possible, even when experiencing cognitive decline. People in such settings have a great deal more freedom of mobility, choice about what and when to eat, and

more control over when they wish to wake and dress. These facilities may also include animals and plants, which bring people “out of themselves” into caring relationships (Gawande, 2014; Brody, 2014). However, these innovative forms of long-term care have worked best in affluent communities, where families have the financial resources to subsidize care.

Revising our systems of care to help people live successfully at home, or in more ethically appropriate long-term care arrangements, is considered by many people to be a moral obligation of a just society. However, there are many unanswered ethical questions. Is there, in fact, an obligation for our society to find ways to support frail elders in their homes and nursing homes? If so, who has such a duty? Does that obligation extend to ensuring equitable access to high quality programs for both the rich and the poor? Who should pay?

Tackling “Macro-Ethical” Policy Questions of Distributive Justice

Ideally, relational ethics leading to a more responsive and caring system could create an opportunity for more openly discussing “macro-ethical” questions of distributive justice (Berlinger, Jennings & Wolf, 2013). Distributive justice arises when resources are limited and decisions must be made about what goals to prioritize. A health system may face a choice between investing in a robust palliative care service and purchasing a proton beam accelerator for prostate cancer treatment. Choosing the latter may have a more positive effect on the bottom line, but the sum of these choices across many systems may burden the nation with excess costs.

The high cost of medicines and new technologies, many of which are used by our aging population, are raising other ethical questions. How do we ensure access to highly beneficial drugs and treatments without creating excessive financial burdens on individuals, families, health care organizations, payers and the nation? Should a health care system offer, or a payer reimburse for, extremely costly drugs that may only extend life by a few weeks or months? How should we balance a patient’s desire for such marginally beneficial medicines with obligations to others in the community?

All developed countries spend much more on the medical needs of their elderly than for other age groups. This makes sense, since health care needs become greater with age and particularly great in the last year of life. However, it is important not to conceptualize the problem of how best to prioritize spending as pitting one age group against another. Daniels has analyzed the problem with doing so, and offers a lifespan approach: “The basic idea is that since we all age,

we should take as a model for what is fair between groups what it is prudent for us to do for ourselves at each stage of life" (Daniels, 2008, page 162).

Our society needs to create fair and transparent processes of deliberation for reaching investment, allocation and payment decisions that maximize to the extent possible, but also within feasible limits, human flourishing at every age. So far in the United States, however, there is little social legitimacy for holding these kinds of conversations. Yet, it is unlikely we can create a just system, one that properly stewards our limited resources, without deliberation about the choices before us (Daniels and Sabin, 2008).

Such deliberations could occur at the national level, particularly with regard to government sponsored health care. However, that is unlikely, since the U.S. Congress has explicitly forbidden the Centers for Medicare and Medicaid Services (CMS) to consider cost data in reimbursement decisions. Increasingly, such conversations are occurring among private payers and within health systems. This trend represents an opportunity to make more conscious decisions at the local level about the kinds of care near the end of life we should prioritize.

Conclusion

Over the last 35 years, from a time when our society didn't know whether withdrawing a ventilator would constitute killing or not, the United States has put in place a robust ethical and legal framework for making bedside treatment decisions for patients near the end of life. It emphasizes autonomy in vitally important ways, but now should expand its focus to include attention to non-maleficence, beneficence, care and justice as well. To do so, we will have to move from an ethics of bedside decision making which focuses strictly on the patient and family faced with a hard decision to an ethics of system reform, which will need to seek new policies and practices capable of better meeting our aging population's medical, social and logistical needs—ideally helping people with chronic conditions and increasing frailty live at home and in the community with greater dignity and meaningful relationships.

Redesigning our systems of care is one of the most important challenges of our time and will take significant moral leadership. Public trust will need to be nurtured so that there can be mature conversations about the reality of death and the wise allocation of resources. New pathways of care will have to be imagined and built. New roles and new economic arrangements may be disruptive, as there will likely be both financial winners and losers. Our society will need mor-

ally courageous hospital trustees, health care executives, payers, policymakers, clinicians, community leaders, patient advocates and families, willing to build new systems of medical care and social support that will challenge the status quo. With courage and commitment, we will improve care delivery, community-based living arrangements, and financing, so that we can, at last, do right by the seriously ill.

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References

- Agency of Human Services, VT.D.o.H. (2013). Patient choice and control at end of life. Retrieved from http://healthvermont.gov/family/end_of_life_care/patient_choice.aspx
- Ayanian, J.Z., Cleary, P.D., Keogh, J.H., Noonan, S.J., David-Kasdan, J.A., & Epstein, A. M. (2004). Physicians' beliefs about racial differences in referral for renal transplantation. *American Journal of Kidney Diseases*, 43(2), 350-357. <http://dx.doi.org/10.1053/j.ajkd.2003.10.022>
- Berlinger, N., Jennings, B., & Wolf, S.M. (2013). *The Hastings Center guidelines for decisions on life-sustaining treatment and care near the end of life: Revised and expanded second edition*: Oxford University Press.
- Blinderman, C.D., Krakauer, E.L., & Solomon, M.Z. (2012). Time to revise the approach to determining cardiopulmonary resuscitation status. *Journal of the American Medical Association*, 307(9), 917-918. <http://dx.doi.org/10.1001/jama.2012.236>
- Brody, J.E. (2014, December 15, 2014). The green house effect: Homes for the elderly to thrive. *The New York Times*. Retrieved from http://well.blogs.nytimes.com/2014/12/15/moving-away-from-nursing-homes/?_r=0

Browning D. & Solomon, M.Z. (2006). Relational learning in pediatric palliative care: Transformative education and the culture of medicine. *Child and Adolescent Psychiatric Clinics of North America*, 15(3), 795-815.

Centers for Medicare and Medicaid Services. (2015). Proposed policy, payment, and quality provisions changes to the Medicare physician fee schedule for calendar year 2016. Retrieved from <https://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2015-Fact-sheets-items/2015-10-30-2.html>

Cintron, A., & Morrison, R.S. (2006). Pain and ethnicity in the United States: A systematic review. *Journal of Palliative Medicine*, 9(6), 1454-1473. <http://dx.doi.org/10.1089/jpm.2006.9.1454>

Cruzan v. Director, Missouri Department of Health, 497 U.S. 111, 110 S.Ct. 2841 (1990).

Daniels, N. (2008). *Just health: Meeting health needs fairly*, Cambridge, UK: Cambridge University Press.

Daniels, N. & Sabin J. (2008). *Setting limits fairly: Learning to share resources for health* (2 ed.). New York: Oxford University Press.

Dresser, R. (1986). Life, death, and incompetent patients: Conceptual infirmities and hidden values in the law. *Arizona Law Review*, 28, 373.

Dresser, R. (2014). Toward a humane death with dementia. *Hastings Center Report*, 44(3), 38-40. <http://dx.doi.org/10.1002/hast.315>

Experts in Chronic Myeloid Leukemia. (2013). The price of drugs for chronic myeloid leukemia (CML) is a reflection of the unsustainable prices of cancer drugs: from the perspective of a large group of CML experts. *Blood*, 121(22), 4439-4442. <http://dx.doi.org/10.1182/blood-2013-03-490003>

Fins, J.J. (2006). *A palliative ethic of care. Clinical wisdom at life's end*. Sudbury, MA: Jones and Bartlett.

Fisch, M.J. (2015). Advance directives: Sometimes necessary but rarely sufficient. *Journal of the American Medical Association, Oncology*, 1(5), 609-610. <http://dx.doi.org/10.1001/jamaoncol.2015.2074>

Fojo, T., & Grady, C. (2009). How much is life worth: Cetuximab, non-small cell lung cancer, and the \$440 billion question. *Jnci-Journal of the National Cancer Institute*, 101(15), 1044-1048. <http://dx.doi.org/10.1093/jnci/djp177>

Garcia, E. (2015). The Village Movement: How Elders are Aging in Place. *Chicago Tonight*. Retrieved from <http://chicagotonight.wttw.com/2015/01/22/village-movement-how-elders-are-aging-place>

Gawande, A. (2014). *Being mortal: Medicine and what matters in the end*: Macmillan.

Gawande, A. (2014, October 4) Can life in a nursing home be made uplifting and purposeful? *The Telegraph*. Retrieved from: <http://www.telegraph.co.uk/culture/books/11139446/Can-life-in-a-nursing-home-be-made-uplifting-and-purposeful.html>

Geige, H.J. (Ed.), Racial and ethnic disparities in diagnosis and treatment: A review of the evidence and a consideration of causes. (2003). *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare*. Washington DC: National Academies Press.

Gillick, M.R. (2006). *The denial of aging: Perpetual youth, eternal life and other dangerous fantasies*. Cambridge, MA: Harvard University Press.

The Hastings Center. (1987) *Guidelines on the termination of life-sustaining treatment and the care of the dying*. Bloomington: Indiana University Press.

Held, V. (2006). *The ethics of care: personal, political, and global*. New York: Oxford University Press.

Himmelstein, D.U., Thorne, D., Warren, E., & Woolhandler, S. (2009). Medical bankruptcy in the United States, 2007: Results of a national study. *The American Journal of Medicine*, 122(8), 741-746. <http://dx.doi.org/10.1016/j.amjmed.2009.04.012>

In re Quinlan, 70 NJ 10, 355 A2d 647, cert denied sub nom Garger v. New Jersey, 429 U.S. 922 (1976).

IOM (Institute of Medicine) Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health, Care (2003). In Smedley, B.D., Stith, A.Y. & Nelson, A.R. (Eds.), *Unequal treatment: Confronting racial and ethnic disparities in health care*. Washington (DC): National Academies Press.

IOM (Institute of Medicine). (2014). *Dying in America: Improving quality and honoring individual preferences near the end of life*. Washington, D.C.: The National Academies Press.

Jennings, B. (2014). Design for dying: New directions in hospice and end of life care. In Kirk, T.W. & Jennings, B. (Eds.) *Hospice ethics: Emerging issues in policy and practice*. New York: Oxford University Press, 285-308.

Kane, L. (2014). Medscape ethics report 2014, part 1: Life, death, and pain. Retrieved from <http://www.medscape.com/features/slideshow/public/ethics2014-part1>

Kaufman, S.R. (2006). *And a time to die: How American hospitals shape the end of life*. Chicago: University of Chicago Press.

Kaufman, S.R. (2015). *Ordinary medicine: extraordinary treatments, longer lives, and where to draw the line*: Duke University Press.

Kelley, A.S., McGarry K., Gogger, R. & Skinner, S. (2015) The burden of health care costs with dementia in the last 5 years of life. *Annals of Internal Medicine*. 163(10), 729 - 36.

Koss, C.S., & Baker, T.A. (2016). Race differences in advance directive completion: The narrowing gap between white and African American older adults. *Journal of Aging & Health*, <http://dx.doi.org/10.1177/0898264316635568>

Levine, C. (2006). *Always on call: When illness turns families into caregivers* (2 ed.). Nashville: Vanderbilt University Press.

Lynn, J. (2004). *Sick to death and not going to take it anymore: Reforming health care for the last years of life*. Berkeley: University of California Press.

MacIntyre, A. (1981). *After Virtue: A Study in Moral Theory*. London: Duckworth.

Meier, D.E., Isaacs, S.L. & Hughes, P.G. (eds.) (2010). *Palliative care: Transforming the care of serious illness*. San Francisco, CA: Jossey Bass.

Menzel, P.T., & Steinbock, B. (2013). Advance directives, dementia, and physician-assisted death. *The Journal of Law, Medicine & Ethics*, 41(2), 484-500. <http://dx.doi.org/10.1111/jlme.12057>

Montello, M. (2014). Narrative ethics. *Hastings Center Report*, 44(s1), S2-S6. <http://dx.doi.org/10.1002/hast.260>

Morrissey M.B. (2011). Phenomenology of pain and suffering: A humanistic perspective on gerontological health and social work. *Journal of Social Work in End of Life and Palliative Care*. 7(1), 14-38.

National POLST Paradigm. (2016). POLST: Physician orders for life-sustaining treatment paradigm. Retrieved from <http://www.polst.org/>

Oregon Health Authority. Death with Dignity Act. Retrieved from <https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/index.aspx>

Petigara, T., & Anderson, G. (2009). Program of all-inclusive care for the elderly. *Health Policy Monitor*.

Pew Research Center. Religious Groups' Views on End-of-Life Issues. Retrieved from: <http://www.pewforum.org/2013/11/21/religious-groups-views-on-end-of-life-issues/>

Powers, M., & Faden, R. (2003). Racial and ethnic disparities in healthcare: An ethical analysis of when and how they matter in *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare*. Washington DC: National Academies Press.

Prasad, V., Kim, C., Burotto, M., & Vandross, A. (2015). The strength of association between surrogate end points and survival in oncology: A systematic review of trial-level meta-analyses. *Journal of the American Medical Association, Internal Medicine*, 175(8), 1389-1398. <http://dx.doi.org/10.1001/jamainternmed.2015.2829>

President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. (1983). Deciding to forego life-sustaining treatment: A report on the ethical, medical and legal issues in treatment decisions: U.S. Printing Office.

Quill, T.E., & Abernethy, A.P. (2013). Generalist plus specialist palliative care-creating a more sustainable model. *New England Journal of Medicine*, 368(13), 1173 - 5.

Rao, J.K., Anderson, L.A., Lin, F.C., & Laux, J.P. (2014). Completion of advance directives among U.S. consumers. *American Journal of Preventive Medicine*, 46(1), 65-70. <http://dx.doi.org/10.1016/j.amepre.2013.09.008>

Rich, S.E., Gruber-Baldini, A.L., Quinn, C.C., & Zimmerman, S.I. (2009). Discussion as a factor in racial disparity in advance directive completion at nursing home admission. *Journal of the American Geriatrics Society*, 57(1), 146-152. <http://dx.doi.org/10.1111/j.1532-5415.2008.02090.x>

Schenker, Y., & Aronold, R. (2015). The next era of palliative care. *Journal of the American Medical Association*, 314(15): 1565 - 1566.

Schmidt, R.J., & Moss, A.H. (2014). Dying on dialysis: The case for a dignified withdrawal. *Clinical Journal of the American Society of Nephrology*, 9(1), 174-180. <http://dx.doi.org/10.2215/cjn.05730513>

Schmidt, T.A., Hickman, S.E., Tolle, S.W., & Brooks, H.S. (2004). The physician orders for life-sustaining treatment program: Oregon emergency medical technicians' practical experiences and attitudes. *Journal of the American Geriatrics Society*, 52(9), 1430-1434. <http://dx.doi.org/10.1111/j.1532-5415.2004.52403.x>

Schulman, K.A., Berlin, J.A., Harless, W., Kerner, J.F., Sistrunk, S., Gersh, B.J., ... Escarce, J. J. (1999). The effect of race and sex on physicians' recommendations for cardiac catheterization. *New England Journal of Medicine*, 340(8), 618-626. <http://dx.doi.org/10.1056/NEJM199902253400806>

Smith, A.K., McCarthy, E.P., Paulk, E., Balboni, T.A., Maciejewski, P.K., Block, S.D., & Prigerson, H.G. (2008). Racial and ethnic differences in advance care planning among patients with cancer: Impact of terminal illness acknowledgment, religiousness, and treatment preferences. *Journal of Clinical Oncology*, 26(25), 4131-4137. <http://dx.doi.org/10.1200/jco.2007.14.8452>

Solomon, M.Z. (1993). How physicians talk about futility: Making words mean too many things. *The Journal of Law, Medicine & Ethics*, 21(2), 231-237. <http://dx.doi.org/10.1111/j.1748-720X.1993.tb01245.x>

Solomon, M.Z. (2014). Modern dying: from securing rights to meeting needs. *Annals of the New York Academy of Sciences*, 1330(1), 105-110. <http://dx.doi.org/10.1111/nyas.12581>

Solomon, M.Z., & Berlinger, N. (2015). Seizing a Medicare moment to improve end-of-life care. *Time*.

Song, M.K., Ward, S.E., Lin, F.C., Hamilton, J.B., Hanson, L.C., Hladik, G.A., & Fine, J.P. (2016). Racial differences in outcomes of an advance care planning intervention for dialysis patients and their surrogates. *Journal of Palliative Medicine*, 19(2), 134-142. <http://dx.doi.org/10.1089/jpm.2015.0232>

Teno, J.M., Gozalo, P.L., Bynum, J.W., & et al. (2013). Change in end-of-life care for Medicare beneficiaries: Site of death, place of care, and health care transitions in 2000, 2005, and 2009. *Journal of the American Medical Association*, 309(5), 470-477. <http://dx.doi.org/10.1001/jama.2012.207624>

Teno, J.M., Mitchell, S.L., Kuo, S.K., Gozalo, P.L., Rhodes, R.L., Lima, J.C., & Mor, V. (2011). Decision-making and outcomes of feeding tube insertion: A five-state study. *Journal of the American Geriatrics Society*, 59(5), 881-886 886p. <http://dx.doi.org/10.1111/j.1532-5415.2011.03385.x>

Teno, J.M., Mitchell, S.L., Skinner, J., Kuo, S., Fisher, E., Intrator, O., ... Mor, V. (2009). Churning: The association between health care transitions and feeding tube insertion for nursing home residents with advanced cognitive impairment. *Journal of Palliative Medicine*, 12(4), 359-362. <http://dx.doi.org/10.1089/jpm.2008.0168>

Unroe K.T., & Meier, D.E. (2013a). Quality of hospice care for individuals with dementia. *Journal of the American Geriatric Society*. 61, 1212-14.

Unroe K.T., & Meier, D.E. (2013b). Research priorities in geriatric palliative care and policy. *Journal of Palliative Medicine*. 166(12), 1503-1508.

U.S. Department of Health and Human Services. (2016). Who needs care? Retrieved from <http://longtermcare.gov/the-basics/who-needs-care/>

Wendler, D., & Rid, A. (2011). Systematic review: The effect on surrogates of making treatment decisions for others. *Annals of Internal Medicine*, 154(5), 336-346. <http://dx.doi.org/10.7326/0003-4819-154-5-201103010-00008>

Winter, L., Parks, S.M., & Diamond, J.J. (2010). Ask a different question, get a different answer: Why living wills are poor guides to care preferences at the end of life. *Journal of Palliative Medicine*, 13(5), 567-572. <http://dx.doi.org/10.1089/jpm.2009.0311>



Advance Health Care Directive

You have the right to give instructions about medical care that someone else to make health care decisions for you in the event of a donation of organs and the designation of a person to change all or any part of it. You are free to change your instructions at any time.

You have the right to:

Name: A
Date: _____

Part 1 — Power of Attorney

(1.1) DESIGNATION OF AGENT
I designate _____ as my agent to make health care decisions for me.
Name of individual you choose: _____
Relationship: _____
Address: (Indicate home or mailing address) if I live with care _____