



# Policy Brief

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## EXAMINING END OF LIFE CARE: CREATING SENSIBLE PUBLIC POLICIES FOR PATIENTS, PROVIDERS, AND PAYERS

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The 17<sup>th</sup> Annual Princeton Conference focused on end-of-life care in the United States. End-of-life care has quality of life, cultural, religious, emotional, economic, community, and political considerations. Most people say they want their end of life to be without pain, surrounded by loved ones, in a comfortable setting. Yet, in their final days, many individuals receive intensive, expensive, and often futile treatment.

This year's conference opened with an overview on the social, economic, and ethical dimensions of end-of-life care. This was followed by a panel session that focused on what other countries are doing and how they are handling the same end-of-life issues that Americans face. From there, a panel examined the research which revealed large variations in end-of-life services and spending across the United States and why this is happening.

Since Medicare and Medicaid, the primary payer of end-of-life care, play an integral role in any policy considerations, the fourth session focused on the quality of nursing home care and specifically the readmission rate for patients to acute care settings. This session was followed by a panel that examined balancing the individual's choice to seek every possible treatment no matter the cost or efficacy vs. establishing a process to assess the value of care.

After the examining some of the challenges in end-of-life care, the conference highlighted the progress being made. Speakers described both public and private successes in end-of-life care programs and how those successes translated to better environments for patients, caregivers, and clinicians. The conference concluded with discussions about next steps and the best ways to take ideas and make them policies. This policy brief presents findings from the 2010 Princeton Conference.

## CHRONIC DISEASE IN THE 21<sup>ST</sup> CENTURY REQUIRES A NEW PERSPECTIVE ON END-OF-LIFE CARE

As people live longer and increasingly with chronic diseases, a reexamination is needed of how end of life is defined and how care is delivered.

**Dr. Joanne Lynn** described how in 1900, Americans lived 46 years on average and died from infections, childbirth, and accidents. Because of this, most people did not need personal care for an extended period of time. When care was needed, family members were the primary caregivers.

As of 2000, the life expectancy increased to 78 and the top causes of death are now long-term illnesses; e.g., cancer, organ system failure, and stroke/dementia. In 1990 there were 11 adults of caregiver age for each adult needing personal care; by 2030 there will be just 6 caregivers per adult needing personal care.

End of life has changed dramatically since the 1900s, replacing short-term illness with long-term illness and requiring us to reconsider how we define and consider the last years of life.

Today, there are three common end-of-life trajectories:

- **Short decline.** In this scenario an individual is diagnosed with a disease like cancer and lives fairly well for a time, and then declines rapidly, often dying in less than two months and possibly entering hospice. This trajectory characterizes about 20% of deaths, with the average age in the mid-60's.
- **Exacerbations.** This trajectory arises mostly with organ system (i.e. heart or lung) failure. The person's function declines slowly over a period of perhaps 2-5 years, with multiple dramatic periods of serious illness and rescue. Dying often seems sudden. About 25% of deaths

follow this course, with average age in the mid-70's.

- **Long decline.** This trajectory is marked by frailty and the need for long-term self-care due to disability, with half having chronic cognitive failure. Function declines over 6-8 years, or even longer. Currently, about half of Americans die under this trajectory and more people will join this category as we prevent illnesses such as those caused by smoking and heart disease. Most people who die after age 80 years are in the long decline trajectory.

Rather than building services to match these different trajectories, our healthcare system built hospice which matches the first trajectory and otherwise focuses on short episodes of service, like treating infections and providing surgeries. We have not reengineered our healthcare system to support people with commonplace chronic, long-term diseases.

Many people believe that we can improve policies for end-of-life care without tackling the challenges of chronic illness and long-term care. This turns out to be false. The category of being "at the end of life" usually turns on a person's projected longevity. But most prognoses are highly uncertain until individuals are very close to death.

If the aim is to provide reliable symptom relief, advance care planning, and family support, then a more useful categorization would capture persons who are seriously ill and disabled with condition(s) that will not substantially improve, will worsen, and will ultimately cause their death. This definition does not include a time frame. Asking clinicians to identify patients whose death is within six months is not a practical way to address the needs of the majority of people who are in their "last phase of life."

For some individuals end of life may be in a few years and the health care priorities should be planning ahead, ensuring comfort, and supporting the family. They



*Dr. Joanne Lynn*

**"IF WE THOUGHT ABOUT HEALTHCARE DIFFERENTLY, WE WOULD BEHAVE AND MANAGE IT DIFFERENTLY."**

should receive optimal (but not excessive) medical care.

There is much already working in caring for those at the end of life. This includes:

- Availability of hospice, palliative care, geriatrics, symptom care (especially pain management), and planning.
- Geographically, specific reforms designed to meet the unique needs of unique populations.
- Identification of those who are doing end of life well and learning from them.
- Normalizing honesty and planning by telling people what they really face.

Other efforts that could work include:

- **Telling stories.** Our culture lacks a healthy vision of death. As a society, all discussions about death focus on avoiding it. People imagine that nothing is worse than death, though most come to realize that there are better and worse ways to live while facing death. The stories that permeate our culture are about miracle saves. We need to change the culture with stories about patients, families, and communities who go through various experiences, allowing the next generation to form preferences and engineer services to match.
- **Organizing political power.** No one likes the status quo. Opportunities exist to generate political power through caregivers and aging persons to address the current crises from high-cost treatments to caregiver shortages.
- **Enabling regional improvement work.** Since delivery is local it is important the communities devise interventions that meet their specific needs.
- **Building capacity for optimal care** is required and must begin with defining the efficiency of specific treatment options and speaking honestly with

patients about their options and potential outcomes.

- **Labeling ordinary dysfunctions as serious errors.** We need outrage over inept transitions, avoidable hospitalizations, manipulating patients, and not planning ahead.

**Jim Lubitz** shared data showing that the portion of Medicare spending devoted to people in their last year of life has been largely unchanged since 1978 at 26-28%. However, spending patterns for Medicare services in their last year have changed dramatically. In 1976, 76% of spending in the last year of life was for inpatient hospital services; in 2006 these services accounted for just 50% of spending. In 2006, skilled nursing facilities represented 10% of Medicare spending in the last year of life, up from just 1.9% in 1978, and hospice services represented another 10% of spending. Hospice services weren't covered by Medicare in 1978, but by 2006, almost 30% of decedents used hospice in their last year.

A conclusion of this analysis is that the use of hospice has not had a large impact on the share of expenditures going to end-of-life care. While the use of hospice has steadily increased, so has the use of both intensive and non-intensive service at the end of life. This includes the percent of decedents undergoing multiple hospitalizations and the percent using ICU services in their last 12 months.

**Dr. Norman Foster** discussed the challenges associated with “futile” care. Medical futility is when a treatment will not achieve the medical goal for which it is designed. Social futility is when a treatment works, but the quality of life does not justify the costs. Extreme social futility is when continuing treatments are provided to patients who have no plausible prospects for leaving the hospital alive or experiencing human interaction. Futile treatment won't go away.



*Dr. Norman Foster*

“THERE IS NO ENTITLEMENT TO ‘ALL-EFFECTIVE CARE’ AND CERTAINLY NOT FUTILE CARE.”

The reasons include:

- **Insistent families.** Clinicians have a duty to honor the wishes of family members. However, in some instances family members may misunderstand the prognosis or have religious views where “giving up” is unacceptable. The family insists on having all possible treatments provided. This raises the question of where clinicians’ duty ends.
- **Legal fears.** Hospitals may render futile care, perceiving potential legal liability for not doing so. Dr. Fost sees this risk to be non-existent. He cannot find one case where a provider is found liable for withholding care over a family’s objection.
- **Political fears.** These fears are real, as denying care—even if futile—can raise a political firestorm (e.g. Schiavo).
- **Hospital culture.** Hospitals are in the business of providing care and as one CEO pointed out, “If you come into this hospital, we’re not going to let you die.”



*Robin Osborn*

“WE HAVE MUCH TO LEARN [ABOUT END-OF-LIFE CARE] FROM OTHER COUNTRIES.”

Discussing futile care is important because if society continues to provide intensive care to all who want it, even if futile, we will never get to a discussion about denying effective care, which is an essential conversation that must be had.

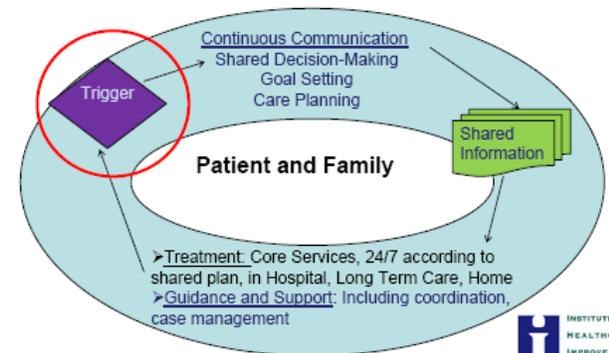
Denying any care is rationing, and rationing continues to be seen as taboo and therefore isn’t discussed. In reality, the question is not whether to ration, but how. People and institutions in positions of leadership need to attack the taboo on explicit rationing so that society can say “no.” Attacking futile care is a place to start.

### PARTICIPANT COMMENTS

- **Cultural issue.** Several participants commented that the main end-of-life issue is cultural. People and their families do everything possible to prolong life, despite suffering, and most clinicians

participate, doing everything they can to prolong life in any situation. We need to change how our culture views death.

- **Entitlement mindset.** People feel entitled to get whatever care they want for themselves or family members. No one wants to give up anything.



- **Patient contact.** Often when critical decisions must be made about the intensity of care to be provided, the people whom the patient trusts most—family members and their primary care physician—aren’t involved in this decision. Such decisions are often driven by specialists. Processes should be changed to involve trusted people in key treatment decisions.

### PERSPECTIVES FROM OTHER COUNTRIES

In this panel, moderator Robin Osborn shared findings from Commonwealth Fund research. The other panelists offered data from Canada and the UK. Perhaps the key theme from this session was that much can be learned by examining end-of-life care in other countries. At the same time, other countries are grappling with the same issues.

**Robin Osborn** indicated that the Commonwealth Fund looks internationally to identify innovations and best practices. A conclusion is that despite differences in financing and delivery systems, all countries want high-quality, patient-centered care. In both the US and the UK, there are initiatives focused

on measuring quality and paying for performance.

On many measures, the US doesn't perform well. This includes per capita spending, out-of-pocket spending, spending per discharge, and number of medical errors. In the US's fragmented delivery system, there are frequent issues with handoffs, high readmission rates, and many patients lacking a long-term relationship with their primary care physician. Just 50% of Americans have had a relationship with their primary care physician for five or more years, compared with 80% of individuals in the UK.

**Andrea Kabcenell** offered observations from the Institute for Healthcare Improvement's (IHI) work studying end-of-life care in Canada, the UK, and the US. This work identified similarities and differences between the US and other countries.

#### Similarities

- **Decision difficulty.** Patients and families have discomfort over decisions. There is reluctance to acknowledge that it is time for hospice.
- **Provider reluctance.** Many healthcare providers have difficulty talking with patients about end-of-life issues.
- **Value of hospice.** Great value is placed on hospice and palliative care in the US and in other countries.

#### Differences

- **Greater anticipation.** In the UK, it seems that an end-of-life patient's future course is more easily anticipated by healthcare providers than in the US
- **Less aggressive care.** In the UK, in some cases less aggressive care is given in the last months of life, including time in the ICU and in the hospital.
- **Additional support.** In the UK, more support is provided over and above medical care than in the US.

IHI's work has led to the development of a framework for early access to end-of-life care and better transitions that can be adopted in any setting for any patient.

This framework is a process where some trigger in the system leads to goal setting, shared decision making, and then a process for continuous communication of the plan of care. What follows is delivery of services, including treatment, guidance, and support. This is an iterative process, in which changing circumstances of the patient may trigger a new round of goal setting and care.

**Dr. Bradford Gray** described the end-of-life care strategy developed in the UK. This strategy was developed because while few people in the UK say they want to die in hospitals, most (58%) do. End-of-life care was a major source of complaint for the National Health Service (NHS) and palliative care was underutilized.

The strategy focuses on a "good death," defined as: being treated as an individual with dignity and respect; being without pain and other symptoms; being in familiar surroundings; being in the company of close family and friends. The strategy is built on existing models and emphasizes identifying appropriate patients and offering them choice and symptom relief. The NHS' end-of-life strategy includes three levels: 1. Societal, to increase public awareness; 2. Infrastructure, with an emphasis on training professional caregivers; and 3. Quality, improving the quality of care for patients. Cost savings is not a part of the rationale for NHS' strategy.

Key building blocks include:

- **The Liverpool Care Pathway.** This pathway includes comfort measures, discontinuation of inappropriate interventions, and attention to physical, psychological, social, spiritual, and religious needs. It also entails providing information to patients and caregivers.



*Dr. Craig Earle*

“IT IS RARE TO HEAR AN ONCOLOGIST SAY, ‘IT IS TIME TO STOP.’”

- **The Gold Standards Framework.** This encompasses the “7 Cs”: communication; coordination of care; control of symptoms; continuity across boundaries (meaning beyond cancer care to other diseases; beyond just hospice and palliative care; beyond particular settings); care in the dying phase; caregiver support; and continued learning.
- **Pathway for providers.** An end-of-life care pathway provides six steps for providers: 1) identifying patients within the last year of life and initiating a discussion of their care preferences; 2) developing a care plan for the patient, based on their preferences and needs; 3) coordinating care across multiple organizations; 4) delivering high-quality care; 5) providing comfort care and good communication in the last days of life; and 6) providing care after death, including care for the patient’s body and assisting with the needs of family and caregivers.

This strategy is physician led, was developed with significant input, and builds upon previous policy initiatives. Indications of physician support are positive. The strategy also has a strong evidence orientation, with surveys about social attitudes and measures of success, such as percent of deaths at home.

Challenges include changing how end of life is viewed (so that death is not seen as a failure), reliably identifying the right patients, overcoming the perception that hospice is charity, and avoiding the perception that this strategy is focused on saving money.

**Dr. Craig Earle** presented data comparing the intensity of treatment of cancer patients at the end of life in the US and Canada. The data shows that in the US, far more patients receive chemotherapy in their last two weeks of life; far more patients are admitted to the ICU; and more patients have more than one hospitalization. This more aggressive treatment does not increase survival.

The possible rationales for futile chemotherapy include patient insistence, clinician optimism, failure to look at “overuse,” and possibly physicians’ financial incentives. In the US physicians can make profits from dispensing chemotherapy drugs, which is not the case in Canada.

Dr. Earle also showed data indicating that the more hospice care that is available, the less likely it is that aggressive care will be provided. The data also shows a big variation on the use of chemotherapy in the 14 days prior to death, indicating different physician practice patterns.

## PARTICIPANT COMMENTS

- **Alternative models.** In the UK when someone is diagnosed with cancer they get a case manager who is a nurse to help them through the care process. In Ontario, Canada, a similar program is being piloted where a group of primary care practices have a nurse practitioner who acts as a navigator, under the direction of the physician, to assist the patient through all phases of the cancer journey.
- **Physician training.** Some participants feel that US payment policies should require that physicians receive training in having conversations with patients about the end of life. As one participant said, “We need to teach physicians to have these conversations.”
- **Talking with patients.** A patient’s oncologist may not be the best person to have a conversation about end of life. The physician may be overly optimistic and the patient and physician may not have a strong relationship. Often patients feel they get the real story from nurses. Perhaps palliative care specialists, hospitalists, or nurses are the right people to have these conversations. More thought needs to be given to this question.
- **Dissimilar cultures.** Participants remarked that Canada and the UK are culturally similar to the US and wondered



*Dr. David Goodman*

**“THE MOST POWERFUL PREDICTOR OF DEATH IN A HOSPITAL (VS. ANOTHER SETTING) WAS AREA HOSPITAL BED SUPPLY—THE CAPACITY IN A REGION.”**



*Dr. Amber Barnato*

**“THERE WAS CLEARLY DIFFERENT CARE FOR THOSE WHO DIED [BETWEEN LOWER- AND HIGHER-INTENSITY HOSPITALS].”**

what might be learned by looking at dissimilar cultures.

### VARIATIONS IN END-OF-LIFE SERVICES AND COSTS

**Dr. Judy Salerno** said there is going to be a renewed spotlight on variation. The Dartmouth Group led the way in showing variation in healthcare costs across geographies and types of service provided. As part of the Health Care Reform Act, there are funds for a commission to look at unjustified variation. Hospice is within the purview of this commission. With that as the context, this panel looked at variation in the cost of end-of-life care and the services delivered.

**Dr. David Goodman** presented data showing wide geographic variation in the percent of decedents enrolled in hospice at the end of life. In some geographies 10-25% of decedents are enrolled in hospice; in other geographies, 40-60% are enrolled.

He also shared data from NCI (National Cancer Institute) treatment centers and academic medical centers showing the following variation:

	Units	Highest	Lowest
Dying in hospital	%	57.1	18.7
Hospice days last month of life	Days	12.5	2.9
Hospital days last month of life	Days	8.4	3.5
ICU days last month of life	Days	4.3	0.4
Receive chemotherapy last two weeks of life	%	12.3	1.4
Patients seeing $\geq 6$ MDs last 6 months of life	%	82.0	26.9

These results are provocative, reflect uneven quality, and are not explained by socioeconomic or clinical factors. This variation in end-of-life care reflects broader problems in the healthcare systems, such as care decisions that often are dominated by the values of healthcare professionals.

The data revealed that high-intensity healthcare creates healthcare system capacity that translates into higher-intensity end-of-life care.

**Dr. Amber Barnato** shared findings from her research into variations in the intensity of ICU care delivered to end-of-life patients. This research took two forms: first, Dr. Barnato and her research team conducted an *in vivo* study looking at the differences in ICU care provided at the end of life at a “lower-intensity” hospital and a “higher-intensity hospital.” These hospitals are in the same healthcare system in the same state. An *in vitro* simulation was also conducted. Each hospital was given the same case study and their actions were observed and measured.

The findings from the *in vivo* study include:

	Lower-Intensity Hospital	Higher-Intensity Hospital
<b>Patients</b>		
What was the case mix?	Few chronically medically ill elders	Many chronically medically ill elders
Was the population culturally diverse?	Not much diversity	Very diverse
<b>Providers</b>		
Who are the Attendings?	Intensivists	Pulmonary specialists
How are the relationships among staff?	Usually collegial	Conflict and tension
What are the goals of patient treatment?	Time-limited trials. The end is discussed in the beginning	Open ended. The end gets discussed when there's nothing left to offer
Does futile treatment occur?	Rare: nipped in the bud	Common: cases drawn out and conflict emerges
Are there sunk costs?	No	Yes - Continued treatment rationalized by prior heavy investment



*Dr. Lisa Shugarman*

“VARIATION DOES NOT HAVE TO BE BAD IF IT IS DRIVEN BY PATIENT PREFERENCES, BUT THESE VARIATIONS [THOSE SHARED BY DR. GOODMAN AND BARNATO] SEEM ATTRIBUTE-ABLE TO PROVIDER PRACTICES.”

Who is in control?	High self-efficacy (internal policies demand this)	Low self-efficacy (externalize control to families and consultants)
What is the state of palliative care?	Mature	New
How do clinicians behave?	Parsimony; evidence-based. Focus on forest	Unrestrained; anecdotal. Focus on trees
A protocol example:	No early tracheostomy	Early tracheostomy
Rounds are for:	Teaching	Work
House staff is:	Independent	Dependent
Attendings are:	Home grown	Mix
<b>Organization</b>		
Hierarchy	Horizontal	Vertical
Incentives	Given to staff	Given to leadership
Motivation	Self-preservation in difficult environment	Status as “the best”

Representative quotes from attending physicians at these facilities include:

- **Lower-intensity:** *“There’s a lot of interest in decision making at the end of life . . . a lot of attention to engaging patients in thinking about whether aggressive care is the right way to go.”*
- **Higher-intensity:** *“When you’re in an environment where it’s also very common to follow a very aggressive mode, a lot of patients will be swept up into that and begin to believe that that’s their goal as well.”*

In the *in vitro* simulation, participants were provided a case study and asked to make decisions about ICU admission, intubation, opiate for symptoms, and more. Researchers observed the decisions that were made, whether preferences were elicited and documented, and if a palliative care consult was suggested.

The results of this simulation were quite comparable between the lower- and higher-intensity hospital. This showed that the decisions made by hospital-based providers when faced with an identical patient are unlikely to contribute to the variation that exists.

Observed variation in end-of-life treatment intensity was found to be related to:

- Variations in the maturity of hospital-based resources and policies.
- The use of explicit treatment goals (e.g., comfort vs. cure).
- Critical care management physician self efficacy pertaining to life-saving treatment.

The conclusion from this research is that patient, environmental, and institutional mechanisms underlie the differences in the intensity of care provided.

## DISCUSSANT & PARTICIPANT COMMENTS

- **Other sources of variation.** The discussants commented that factors such as age, gender, and race contribute to the variation within healthcare.
- **Patient-driven variation.** Discussant [Dr. Lisa Shugarman](#) observed that variation is not inherently bad, if it is variation driven by differences in patient preferences. However, the research shared by the presenters seemed to show variation that is driven not by patient preferences, but by provider supply, provider practices and norms, and systemic cultural issues.
- **Hospice variation.** Discussant [Dr. Kimberly Johnson](#) said that on a county-by-county basis, participation in hospice programs among African Americans ranges from 0% to 60%, showing that local factors play an enormous role. These include marketing

and outreach effort, the racial makeup of the staff, and more. This shows that variation is complex, driven by a host of factors that are often very difficult to explain.

- **Upstream data collection.** An insight from Dr. Barnato's research that several participants found interesting was that in the lower-intensity hospital, in the simulation exercise, several MDs were looking for data in the chart that wasn't there. It shows that upstream data gathering may play a role in the end-of-life decisions and treatment made in the hospital/ICU.
- **Hospital accountability.** An initiative related to payment reform in Massachusetts requires that hospitals be able to document patient preferences in order to get paid. This forces greater provider accountability.
- **Systemic factors.** The fact that physicians at the lower- and higher-intensity hospitals made similar decisions in the simulation exercise would indicate that the causes of variation are systemic. However, some participants said that the simulation exercise didn't accurately mirror the real world and the many cultural, social, and environmental factors that affect real-world decisions.



*Dr. Joseph Ouslander*

**“OF 200 HOSPITALIZATIONS [OF NH RESIDENTS], AN EXPERT CLINICAL PANEL RATED TWO-THIRDS AS POTENTIALLY AVOIDABLE.”**

### **NURSING HOME PATIENT READMISSIONS TO ACUTE CARE SETTINGS**

This session focused on improving transitions in and out of nursing homes to decrease hospital readmissions. Doing so may require new policies, incentives, and tools.

**Dr. Marie Bernard**, who moderated this session and who has previously served as a nursing home (NH) geriatrician, provided an example of a typical scenario.

At 2 a.m. the on-call geriatrician gets a call from the nursing home. A patient (who probably has a chronic disease) fell. There is

no electronic medical record, no documentation about the patient, and the person calling from the nursing home is new, with no knowledge of the patient. The geriatrician is under pressure to decide what to do. If the geriatrician decides that the patient should stay at the nursing home, the nurse at the NH will complain, “We don't have the resources here to take care of this patient.” There is a low threshold to move the patient to the hospital; all incentives are to do so.

The presenters and discussants shared their views on how to improve avoidable rehospitalizations of NH residents, including ideas regarding policy changes. Dr. Shari Ling from CMS discussed steps the government is taking to promote high-quality end-of-life care.

**Dr. Joseph Ouslander** said that rehospitalization of NH residents is common, expensive, often traumatic, and fraught with complications. Of the 1.8 million SNF admissions in 2006, 23.5% were readmitted to an acute hospital within 30 days at a total cost of \$4.3 billion (Mor et al. *Health Affairs* 29 (No. 1): 57-64, 2010). Several studies suggest that the most common diagnoses associated with readmission are CHF, pneumonia, and urinary tract and other infections.

A study from 2000 (Saliba et al, *J Amer Geriatric Soc* 48:154-163, 2000) found that as many as 45% of admissions of NH residents to acute hospitals rated as inappropriate. In 2010, a CMS Special Study found that 67% of hospitalizations by NH residents are potentially avoidable (Ouslander et al: *J Amer Ger Soc* 58: 627-635, 2010).

This CMS Special Study found the following factors to be important in reducing avoidable hospitalizations: improving the quality of care for assessing acute changes; lack of availability of on-site physician or nurse practitioners; an ability to obtain stat lab tests and initiate IV fluids; improved advance care planning; and providing less futile care in terms of frequent

hospitalizations at the end of life.

Addressing these factors requires more resources and infrastructure in the SNF setting, including more trained licensed nurses, and more availability of physicians, nurse practitioners, or physician assistants.

### What Can Be Done?

Dr. Ouslander offered the following suggestions:

- **Financial incentives**, such as bundled payments and P4P.
- **Regulatory incentives.** Incentives can address the assessment of acute change in condition and advance directives in the survey process.
- **Limit liability.** Tort reform that limits damages for “pain and suffering” in end-of-life care.
- **Educate patients and families.** The goal is to create realistic expectations.
- **Improve NH infrastructure.** This includes the workforce and the ability to provide ancillary services.
- **Guidelines and tools.** These will help ensure quality and improve everyday clinical practice.

**Tom Ventura** described the QIO (Quality Improvement Organization) Care Transitions Initiative and the care transition changes his organization in Colorado is driving. This QIO Initiative involves 14 competitively awarded QIOs which have an evaluation measure of reducing 30-day hospital readmissions among Medicare FFS beneficiaries. The initiative targets a community of beneficiaries defined by geography of residence. The general QIO strategy is to:

1. **Define the community** using Medicare claims data to establish a stable population of beneficiaries and the providers most involved in providing medical services to the population.

2. **Engage providers serving the population** to work towards reducing unwanted hospital readmissions.
3. **Identify and target problematic utilization patterns** through examinations of claims data and root cause analyses of readmissions.
4. **Implement evidence-based interventions and tools.** The specific interventions implemented vary based on the existing priorities and activities of the community and the QIO’s insights on key drivers of readmissions affecting the targeted population.
5. **Measure progress through intervention success and patient outcomes.**

Aggregation of knowledge from the 14 communities demonstrates 3 basic drivers of hospital readmissions:

- Poor or nonexistent methods for incorporating patients and families in transitional care.
- Lack of standard and known processes for transferring or transitioning patients and responsibility for care across settings.
- Unreliable medical care information transfer.

Commonly used evidence-based interventions include:

- **A variety of formal programs and tool kits**, such as the Care Transitions Intervention, Transitional Care Nursing model, the InterAct toolkit, Project RED, and Project BOOST.
- **Patient activation** through transitions coaching, patient-directed/driven discharge preparation checklists, and standardized use of teach-back methods.
- **Deployment of standard and known process support tools** such as provider discharge task checklists, discharge document standardization, enhanced risk assessment and referral support, and provider education.

- **Enhanced information transfer** through common information transfer tools, structured communication support (SBAR), communication design, and advanced care planning tools.

In Colorado, the Palliative Care Community Action Team is creating a resource compendium (by aggregating resources that already exist) and is leading a provider education campaign. The goal is to plant seeds for improving referrals to palliative care and hospice.

**Dr. David Stevenson** focused on the policy goal of providing high-quality, efficient palliative and end-of-life care for NH residents. Improving transitions and reducing avoidable hospitalizations play important roles.

Nursing homes play an important role in end-of-life care. Of the roughly 1 million people each year who don't die in a hospital, many of these individuals die in nursing homes and assisted living facilities. As the population ages, this number will increase.

In nursing homes, end-of-life care can be provided in combination with long-term supportive services for residents at the end of life. If residents elect to enroll in the Medicare hospice benefit, the hospice services can be provided alongside NH care (importantly, hospice and SNF care cannot be used in combination for the same condition). Whether delivered in the context of hospice or not, palliative care can be provided throughout a nursing home stay (e.g., even for residents receiving shorter-term rehabilitative care).

Hospice initially focused on individuals with cancer diagnoses receiving services at home, but hospice has been broadened to include other types of patients and settings. About 25% of hospice users are in NHs. Hospice use and spending have grown substantially and now represent about \$11 billion—with spending levels expected to double over the next decade. Studies have shown multiple benefits from hospice programs including

improved pain assessment and management and decreased hospitalization in the last 30 days of life.

In contemplating future policies related to NHs and hospice, the following questions must be addressed:

- **Benefit reform.** Is a new or reformed end-of-life benefit needed for NH residents? Are palliative and end-of-life care components of high-quality NH care?
- **Payment reform.** How can financial incentives to elevate palliative care be balanced with mitigating incentives for hospitalization and other costly, intensive services?
- **Delivery system reform.** Should the responsibility for end-of-life care reside with NHs or hospice agencies? What policies are needed to ensure that all entities have the resources and expertise to succeed?
- **Regulatory reform.** How can end-of-life quality measures be integrated into an assessment culture that has prioritized restoration and maintenance of functioning?

The bottom line is tools like INTERACT and QIO efforts can lead to meaningful change if accompanied by more coherent policies.

Further policy changes are likely to be needed to incent and support the infrastructure needed to achieve sustainable positive change.

**Dr. Shari Ling from CMS** focused her remarks on mechanisms to promote high-quality end-of-life care. Among the key mechanisms are:

- **Public reporting of quality measures.** Healthcare Reform (PPACA) legislation requires that in 2012 the Secretary of Health and Human Services must publish quality measures and a data requirement



*Dr. David Stevenson*

**“PAYMENT REFORM SEEMS ESSENTIAL BUT ONLY IF PROVIDERS HAVE ADEQUATE RESOURCES AND EXPERTISE.”**

timeline along with 10 or more patient outcomes.

- **Payment incentives** such as pay-for-reporting and pay-for-performance, and pay-for-value (value-based purchasing). The PPACA reduces payments for readmission and provides funding for improved care transition services.

Other mechanisms include state surveys, conditions of participation, and monitoring programmatic influence.

Among the challenges faced are the infrastructure and capabilities for data collection, as well as the culture change that is required. Today data collection is in silos. This will need to change to become standardized and comprehensive. Questions remain about what aspects of quality of care are meaningful and should be reported to the public and what aspects of care are valuable.



*Dr. Thomas Murray*

**“WE NEED TO TELL STORIES ABOUT THE ENDING OF LIVES, ABOUT PEOPLE WHO DIED AS RICHLY AS THEY LIVED, SUPPORTED BY HUMAN RELATIONSHIPS.”**

## PARTICIPANT COMMENTS

- **Bundled payment.** Participants agree that bundling will force more coordinated care. However, it is not clear how the money in the bundles will be divided and there is some concern that hospitals and ACOs may not provide adequate infrastructure outside of the hospital to decrease hospitalization. Some participants felt that on a local basis, the QIOs might provide some of the infrastructure that is needed to assist with transitions and would therefore share in the bundle.
- **Include families.** The comment was made that families must be included as part of the quality metrics.

## ETHICAL ISSUES SURROUNDING END-OF-LIFE HEALTHCARE

Dr. Thomas Murray and Dr. Tom Rosenthal each discussed critical ethical issues related to end-of-life care.

**Dr. Murray** concurred with comments made throughout the conference’s first day about the need for stories. He noted that many of the stories and images in our society are about vibrant, healthy older people and the curative power of technology. These images and stories, however, do not talk about the cost or about the role of death.

End-of-life narratives often neglect the role of caregivers, yet 75-80% of community-based long-term care comes from families. Between 30 and 38 million adults are caregivers for other family members. Their average commitment is 21 hours per week. Among caregivers, 54% are women, 13% are over age 65, and about 33% have their own health issues. As we age, we may increasingly be in need of care as we concurrently deliver care to others.

Dr. Murray pointed out that the need to care for others illustrates that we live in a network of relationships. If life is about a web of relationships then the end of life should also be about relationships.

The consensus in the field of biomedical decision making is built around the model of a competent individual making decisions. But this model has limits because people can not always competently speak and decide for themselves. That is why advance directives, living wills (though often too limited), and durable powers of attorney (pick someone you trust) are so important.

These types of directives are so important because end-of-life decisions are complex and can involve forgoing certain treatment, and (about 50% of the time) these decisions involve conflict of some type. Usually—but not always—these conflicts are resolved.

**Dr. Rosenthal**, the Chief Medical Officer at UCLA Medical Center, described the difficulty hospitals face when patients and their families demand futile care.

He gave an example of a 68-year-old patient with multiple medical problems whose prognosis for leaving the hospital was nil. The patient was initially competent and agreed to the treatment. The care being delivered—including 24 intravenous drips which over three months cost about \$1 million—was futile. It wasted resources (i.e. a bed that could have been used by someone else) and was demoralizing to the staff. However, when the patient was no longer competent, the family was adamant in wanting this care continued. Dr. Rosenthal said that similar cases arise at UCLA Medical Center every few weeks.

Dr. Rosenthal indicated that economic self interest played no role in continuing to care for this patient. He said the staff believed the treatment was inflicting suffering and the patient's culture was clearly a factor in the family's desire to continue having care provided. Among the ethical questions raised is whether the hospital should have withdrawn care over the family's strong objection.

### PARTICIPANT COMMENTS

- **Medically necessary.** Some participants argued that if care is medically necessary, it should always be provided and covered. However, if care is not deemed as medically necessary (as was the case in this example) then an individual may choose to pay on an out-of-pocket basis, but society should not pay. (Regardless of what the clinicians believed, this particular family would have argued care was medically necessary.)
- **Hospital culture.** One participant said that a lower-intensity hospital would not have allowed this to happen; hydration would have occurred on the floor, not 24 drips in the ICU. This participant suggested that UCLA's culture allowed this to happen. (Others disagreed, saying that this was not just a function of UCLA's culture but reflects society's culture.)

- **Lack of conversations.** A major problem is that our society cannot have a conversation about futile care. If we cannot talk about it we cannot do anything about it. Furthermore, if we cannot discuss futile care, we certainly cannot move towards a discussion of cost-effective care, known to some as a euphemism for rationing.
- **More scholarship required.** Part of initiating a conversation about death is having more scholarship on the topic.
- **Essence of palliative care.** Understanding definitions is crucial. Palliative care is not rationing. It is matching the care provided with what a patient wants. Arguably no rational person would be against palliative care.
- **Limiting futile care.** Some participants said that just because a patient wants a certain level of care does not mean that they should automatically receive it. There are social consequences to allowing people to do whatever they want. Someone has to say "no" in some situations. It is not always possible or appropriate for an individual physician to say no to an individual patient. There need to be societal limits and a process to get there.

Studies show that not many patients, when informed, want the most aggressive care. Some participants suggested that because so few patients will want the most aggressive care, society can afford to pay for these outliers.

### PROVIDER, DELIVERY SYSTEM, CAREGIVER, AND INSURER END-OF-LIFE CONSIDERATIONS AND INNOVATIONS: WHAT ARE THE PROMISING PRACTICES AND CURRENT CHALLENGES

In this session the presenters described new and innovative end-of-life programs that are working. These are programs that are

showing great promise and that could be replicated in other settings.

**Karen Wolk Feinstein**, president & CEO of the Jewish Healthcare Foundation in Pittsburgh, Pennsylvania, explained that the Jewish Healthcare Foundation has funded many programs dealing with end of life, including hospice and palliative care programs. One program that stands out and that could be replicated is Closure. The Closure program is a series of conversations about end of life. Clinicians and caregivers are exposed to the program by attending six monthly sessions totaling 18 hours. These sessions deal with an overview of the issues, values, resources and implementation, family and provider experiences, planning tools, and planning for culture change. Closure has specific talking points dealing with society, the health system, family, and providers.



*Dr. Susan Tolle*

**“A NEW STANDARD OF END-OF-LIFE CARE WILL BE WHEN ADVANCE CARE PLANNING BECOMES THE NORM.”**

The Closure vision is for patients and loved ones to be informed about end-of-life choices and challenges. It envisions making resources, support systems, curricula, and planning tools widely accessible in all settings. The main goal is for end-of-life issues to be openly discussed in a context where the end of life is viewed as both meaningful and personal. (For more information, see [www.closure.org](http://www.closure.org).)

**Dr. Susan Tolle** described the POLST initiative (Physician Orders for Life-Sustaining Treatment), how it works, and how it is evolving.

POLST is a program that is designed to honor the wishes of patients to have or to limit various medical interventions. The table below shows how it is different from an advance directive.

**Differences Between POLST & Advance Directive**

	<b>Advance Directive</b>	<b>POLST</b>
For whom	All adults to express preferences for <i>future</i> treatments	Persons of any age with advanced illness to guide <i>current</i> treatment
Purpose	To express values and appoint a surrogate	Medical orders that turn a patient’s values into action
Guide actions by emergency medical personnel	Usually not	Yes

POLST is for people with “advanced illness,” which should not be equated with the end of life. It focuses on the current condition of the patient so a health care professional will know from the patient’s perspective, “Do you want this specific treatment?” POLST provides immediately actionable information. The power of a POLST program is in the decision of a patient about the type of medical interventions they want. Options include *Full Treatment, Limited Additional Interventions, or Comfort Measures Only*.

In 1990, the first POLST program was being developed in Oregon. As of 2010, 8 states have endorsed POLST programs and 25 other states are developing programs. States develop POLST programs differently; some have legislation and others have regulation. (Dr. Tolle advocates legislation if possible). In states with a POLST program, it is entirely voluntary; no one has to complete a POLST form, and when completed POLST orders can be revoked or changed at any time by the patient or legally authorized surrogate.

Several studies have measured the effectiveness of POLST programs. These studies have shown that nursing home residents

with POLST orders of *DNR/ Comfort Measures Only* had these orders followed 100% of the time, and 5% of patients died in an acute care hospitals. (The few patients who died in a hospital were moved because the comfort measures could not have been provided in their former care setting.)

Having a POLST program become widely implemented takes a long time. The process requires educating health care professionals and the public, and may require policy reform. In Oregon, the state is taking the POLST program to the next level by creating a freestanding state-wide POLST registry that is accessible by emergency providers.

**Dr. Randall Krakauer** shared information about Aetna's successful Compassionate Care<sup>SM</sup> Program. The goal of this program is to provide additional support to terminally ill members and their families, and to help them access optimal care. The goal is not an outcomes goal; it is a process goal. The belief is that achieving the process goal will lead to improved outcomes. For more information see:

([www.aetnacompassionatecareprogram.com](http://www.aetnacompassionatecareprogram.com))

This program has the following components:

- **Specialized case management services.** Nurse case managers are the key to the program's success. These individuals are trained and experienced in care and management of patients with terminal illnesses. Their focus is to engage members and their families, caregivers, and physicians to initiate discussions about options.

The case managers help coordinate medical care, facilitate palliative care and pain relief, and coordinate benefits and community-based services. They help members with advance directives, including living wills, durable powers of attorney, and estate plans. They also provide psychological support for the

members, families, and caregivers, and remain in contact as long as it is helpful. The case managers are adept at building relationships over the phone and dealing with cultural sensitivities.

- **Enhanced hospice benefits.** The typical hospice benefit requires a patient forgo "curative treatment" of their condition. In addition, a physician must certify the patient is likely to die within 6 months. In this program, Aetna has liberalized the benefits for commercial members (but not Medicare members, whose benefit is defined by CMS) and removed what often seem to be artificial barriers. A patient may continue curative treatment and definition of "terminal" was expanded from 6 to 12 months one is expected to live. When benefits were liberalized in association with case management there was no increased cost and results were comparable to the case management alone group. Positively, members (and their families) in this program were happier compared to their counterparts.

As a result mostly of case management, the proportion of members using hospice increased dramatically to 71% for Aetna's commercial members. In addition, the average number of days of hospice nearly doubled.

Dr. Krakauer explained that in addition to a great deal of positive feedback and many outstanding anecdotes, analysis of case management program results shows that Medicare Advantage members have 82% fewer acute inpatient days, fewer ER visits, and 88% fewer ICU days. This program shows that highly trained case managers and liberalization of hospice benefits can result in a positive experience for members and their families, with a decreased use of resources. The implications of this program include taking the lessons from this program and reapplying them, as well as supporting policies to liberalize the Medicare hospice.

**Dr. Thomas Edes** described the transformation taking place in the Department of Veterans Affairs (VA) end-of-life programs. As background, over 25% of all Americans who die this year will be veterans. More veterans will die this year than died during World War II.

According to Dr. Edes, as of 2001, the VA did not have a workload capture system to track how many veterans received hospice and palliative care, and the mechanisms in place for VA-purchased hospice were not adequate. Data from VA analysis indicated that about half of those veterans who died as VA inpatients would have chosen palliative care if it was available.

However, many VA hospitals had no formal palliative care inpatient programs and many VA facilities did not purchase home hospice care. After this assessment in 2001, the VA embarked on a comprehensive multi-faceted initiative to improve access, quality, and reliability of end-of-life care for all veterans, in all settings. Key aspects of this program included establishing palliative care programs and training at every VA facility and establishing a national Hospice-Veteran Partnership program.

Between 2001 and 2004, major progress took place in the VA's Palliative Care services. These changes included:

2001	2004
Low use of community hospice	Hospice-Veteran Partnerships to strengthen ties with community hospices
Many unaware of hospice benefits	Revised hospice policy, with community participation
Half of VA facilities purchased no home hospice care	FY04 first VA budget in history to specify home hospice; offered to all enrolled veterans
27% of VA facilities did not refer patients to hospice	National policy for home hospice referral and purchase

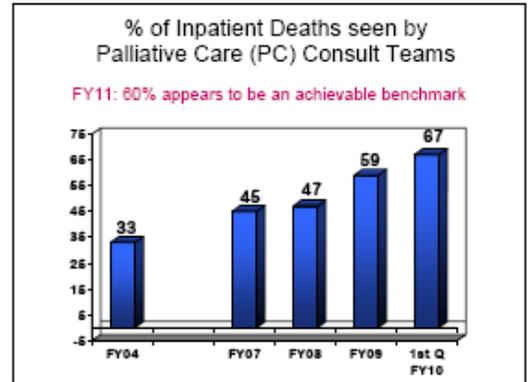


*James Brooks*

**“END OF LIFE IS A SPIRITUAL EVENT WITH MEDICAL IMPLICATIONS.”**

No reliable data	Workload capture in all settings
38% of VAs with no inpatient HPC programs	Palliative care teams in every VA
Few trained in palliative care	Fellowships and other training programs
Low use in all settings	Escalate use and elevate expectations

Between 2001 and 2003, the percent of VA hospitals with palliative care programs rose from 38% to 84%. As of FY 2009, 59% of all VA inpatient deaths had an associated palliative care consult (up from 33% in FY 2004) and 33% of inpatient deaths occurred in hospice beds.



The average daily number of veterans receiving VA-paid home hospice care has increased from 77 in FY 03 to 164 in FY 04 to 961 in FY 09. Other key improvements include an increase in the documentation of discussions about veterans' goals of care; increased use of advance directives; more frequent chaplain visits; a significant increase in the bereavement contact after the veteran's death; and higher family satisfaction. VA data shows that as the use of hospice has increased, veteran deaths in the ICU, acute settings, and nursing homes have decreased, all guided by the program's mission to honor veterans' preferences for care at the end of life.

**James Brooks**, the lone clergy member on the panel and the executive director of Project Compassion, offered his reflections. He recalled an uncle who had advanced

prostate cancer who chose not to have it aggressively treated. He received hospice care, pain management, and support from his community. On his last day, his wife kissed him, which caused him to say, “Better than medicine.” This act of caring showed Mr. Brooks that dying is about relationships and community.

While our society tends to view death as a medical event, it is not. It is a spiritual event. Medicine provides some degree of help and comfort. Death should be viewed not from a medical perspective but from the perspective of the whole person. It should be thought about from the perspective of communities, neighbors, social networks, and organizations—the nexus of relationships that each person has.

It is important to keep in mind that the hospice movement started as a volunteer effort, before becoming professionalized and reimbursed. It is delivered on a local/community basis and is part of the community.

Project Compassion partners with about 100 organizations to train “circles of care and support.” The idea is to train people to provide the community-based support that is needed. The goal is to increase the community-level awareness of various resources related to end of life, such as advanced care planning.

**Len Fishman** of Hebrew SeniorLife provided his perspective. He suggested that one of the key messages from this conference is the need for more positive stories about end-of-life care.

Mr. Fishman specified that an area of particular importance is the alignment between hospitals and skilled nursing facilities (SNFs). Greater alignment is needed between these two entities. One way to accomplish this could be through bundled payments. This mechanism will have challenges, but bundling will force hospitals

to become more aligned with SNFs to decrease readmissions.

One project in which Mr. Fishman is involved is termed “The Conversation Project.” This project was initiated to ensure that individuals and our society have conversations about the end of life. The challenge is to change the cultural context for having this conversation.

## PARTICIPANT COMMENTS

- **Use of POLST.** In Oregon, most of those who die have a POLST form and all long-term care facilities are using POLST. It is also being used in assisted living and retirement communities.
- **Toolkits for capacity building.** James Brooks said tools are available to help communities build their capacity for dealing with end-of-life issues. Many good tools can be found at [www.caringinfo.org](http://www.caringinfo.org). Also, POLST has a series of train-the-trainer tools.
- **Importance of language.** Several participants agreed with Dr. Tolle’s comment about the importance of language used in discussing end-of-life care, such as the language on the POLST form. One participant asked whether the terms should be “end-of-life caring” instead of “end-of-life care.” The word “care” seems to focus on medicine while “caring” conveys the communal ideas of caring for someone. (Dr. Tolle said that POLST doesn’t use the term “end of life,” using words like “advanced illness” and “frailty.”)
- **Barriers to a POLST registry.** In Oregon one centralized registry of POLST information is accessible to emergency responders through a statewide emergency medical system. However, such a system isn’t able to be copied in many states, where emergency services are provided at the county level (not the state level) and there are not integrated systems.

- **Getting MD support.** Most physicians believe they are the leader in having end-of-life conversations. However, 91% of conversations are not held with MDs. End-of-life conversations are usually with other healthcare providers, such as nurses, social workers, and case managers. There remains an opportunity to educate physicians, get their support, and change their practice patterns.
- **Policies for POLST.** It is true that using POLST forms where patients request comfort measures only can decrease revenue for hospitals by decreasing the amount of services offered. As a result, some hospitals are not working to make POLST information readily available or quickly accessible to their clinicians.

### NEXT STEPS IN CREATING END-OF-LIFE POLICIES

**Stuart Altman** provided the context for this session by suggesting that policy changes may be needed related to end-of-life care. The reality is that a small percent of the population accounts for a disproportionate portion of healthcare spending. This includes many people in their last year of life.

Dr. Altman noted that throughout the conference, presenters described successful programs. These programs all emphasize quality of life; not cost savings. These programs have been voluntary. While not their stated intent, these programs have decreased the use of healthcare resources and have decreased costs. Longer term, perhaps such programs must become mandatory; not voluntary. Something usually becomes mandatory only after it has been voluntary for a considerable time and after extensive data exists to support why policies should be changed. (An analogy is that wearing seatbelts used to be optional but was made mandatory.)

**Angie Truesdale** shared her perspective as the Director of Public Policy for the National Hospice & Palliative Care Organization (NHPCO).

From NHPCO's perspective, the hospice benefit is a Medicare success. In 2008, 1.5 million Medicare beneficiaries received hospice; slightly more than 1 million of these individuals died in 2008. Total Medicare hospice spending was about \$11.2 billion (up from \$2.9 billion in 2000).

The increase in spending is due to a continuing increase in the use of hospice by Medicare beneficiaries, as well as steady growth in the period of time that hospice is used, from just under 50 days on average in 2001 to about 70 days on average in 2008.



Amid the increased spending on hospice, NHPCO is engaged in an ongoing effort to protect the current Medicare hospice benefit. She pointed to a recent Duke study indicating that on average, hospice saves \$2,300 per patient. And, for the majority of patients, costs would be reduced if hospice were used for a longer period.

Based on the benefits of hospice, NHPCO is interested in policy changes to support two new models of care. These models are:

- **Concurrent care.** Today, if a patient elects to receive hospice, Medicare rules require that the individual must decline any healthcare services covered by Medicare Part A. Under the new model, patients who are terminally ill with a six-month prognosis could receive both a full range of hospice services and a full range of conventional medical services, covered by Medicare. A 15-site demonstration of this model was included as part of the healthcare reform legislation.
- **Transition care management.** In this model, patients must be terminally ill with a life expectancy of 18 months or less. Patients and families would have access to a full range of conventional therapies and reimbursement would be based on a consultative model, where a physician's fee schedule would vary based on the professional delivering the services. This model has been discussed for more than ten years but has not yet been introduced into legislation. It is part of NHPCO's legislative agenda.

For both of these models, the expected outcomes are lower costs due to decreased use of hospital services, along with higher patient satisfaction.

**Dr. Brent Pawlecki** offered the perspective of Pitney Bowes (PB), a major employer with more than 35,000 employees, including over 24,000 in the United States.

Why is end of life an issue for employers? One reason is because many workers are caregivers. The responsibilities of a caregiver have a dramatic impact on a worker's productivity. Citing internal data, employees who are caregivers often experience workday interruptions and 60% need to attend to some kind of crisis. The cost to an employer of having an employee who is a caregiver is more than \$2,100 per year. Furthermore, many employees become caregivers unexpectedly and are not prepared. They often have not discussed

end-of-life issues with their parents and family members. Discussions about the end of life generally occur "late, too late, or not at all." In addition, many caregivers suffer adverse health effects as they care for others but not themselves.

To address these issues, PB incorporates end-of-life issues into its wellness programs that are designed to provide employees with the environment, tools, and motivation to enhance their health and well-being. This includes a 15-minute online course, "Planning for the Future." The course encourages employees to have conversations with loved ones about the future, discussing issues such as end of life. Employees are also provided with information about related services such as financial planning and legal services.

Pitney Bowes conducted a survey to understand the impact of caregiving on its employees. About 18% of employees were self-identifying as current caregivers and 10% previously had been. Surprisingly, 18% of current caregivers are in the 30–40 year-old age range. About half of all caregivers are caring for more than one person. (The more people being cared for by a caregiver, the greater the toll.) Perhaps the most important statistic from a business perspective was the finding that among caregivers, 20% are considering leaving the workforce.

A resource suggested by Dr. Pawlecki with tools and information is Caring Connections at [www.caringinfo.org/employer](http://www.caringinfo.org/employer).

**Dr. Ira Byock** described some of the challenges that come from looking at end of life as a healthcare issue. Healthcare (i.e., medicine) is problem based. It is focused on treating diseases and injuries; people aren't served until they become a patient. But dying is not medical; it is personal. An individual gets a diagnosis, but a family gets an illness.



*Dr. Ira Byock*

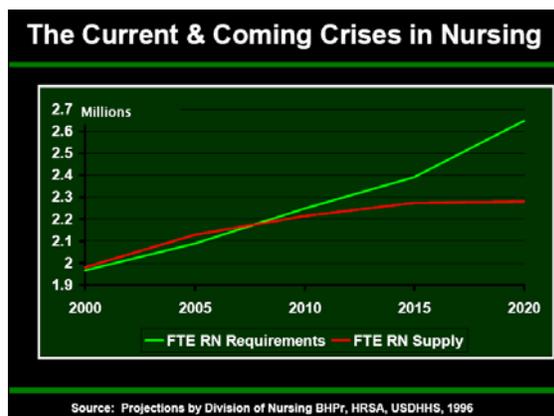
**“WE CAN’T FIX THE END OF LIFE BY MERELY FIXING HEALTHCARE...IF ALL WE DO IS IMPROVE MEDICAL TREATMENT FOR DYING PEOPLE... THE BEST WE WILL ACHIEVE IS A BETTER MEDICAL EXPERIENCE OF DYING.”**

The burden on caregivers is immense. More than one in five adults in the United States is a caregiver. When a family has a member with a serious illness, 29% reported losing most or their entire major source of income and 31% reported losing most or all of their family savings.

Dr. Byock said what families value at the end of life is:

- **Ensuring the “best care possible”**
- **Feeling their preferences were followed**
- **Knowing the person was treated in a dignified manner**
- **Having a chance to say and do the things that matter most**
- **Honoring and celebrating the person in his/her passing**
- **Having a chance to grieve together.**

These values cannot be respected without community and mutual responsiveness. This will become increasingly difficult with smaller families and therefore fewer caregivers. In 1990, there were 11 people for each person in need of caregiver support; in 2030 the ratio will be 6:1. In addition to a shortage of caregivers, there will also be a shortage of nurses.



Communities matter because they care for people; not patients. Communities have local leaders and include congregations, neighborhoods, schools, nonprofits, social

clubs, fire and police, and much more. Communities are people who care for each other.

In addition to communities, thinking beyond healthcare to improve the end of life will take advocacy and activism. Dr. Byock and colleagues created the Reclaiming the End of Life Initiative ([www.reclaimtheend.org](http://www.reclaimtheend.org)), a project to bring attention to end-of-life issues, during the 2007 New Hampshire presidential primary. Forums conducted by this organization have found that more than 80% of people say it is extremely or very important that: dignity is respected; preferences are honored; pain is controlled; and family members are not left with debt. Reclaiming the End also found that fewer than 50% of people strongly endorsed being kept alive as long as possible. (This is the kind of data that policymakers should know.)

From a policy perspective, Dr. Byock and his co-authors concluded that by focusing on actions in which consensus exists, public officials and candidates can respond to problems and improve the care and experience for frail elders, dying Americans, and their families.

Some of the policy levers listed by Dr. Byock are:

- **Eliminating the statutory-regulatory distinction between curative and palliative care**
- **Requiring insurers to include hospice and palliative care as a benefit similar to Medicare**
- **Expanding funding for senior centers and aging services**
- **Requiring adequate staffing of aides in skilled nursing facilities, long-term care homes, and assisted living facilities.**
- **Grants to civic and faith-based organizations for home care to frail elders and ill people**

- **Tax deductions for family caregiving expenses**
- **Expanded NIH/AHRQ support for research in family caregiving, secondary prevention, and community-based services.**

## PARTICIPANT COMMENTS

- **Reconceptualizing hospice.** Some participants believe it is necessary to reconceptualize hospice. In doing so, much more data is needed to measure the economics of hospice; there is little data in this area.
- **Pressures on politicians.** Some participants feel that the cynical public believes anything government does is economically motivated. Therefore, in order for any policy changes to occur related to end of life, policies will have to focus on quality of life, and not cost. Politicians will simply not be able to pursue policies related to end of life that have even a hint of cost reduction. (A participant told how early in his career he linked living wills and cost, and received tremendous criticism.)

However, others argued that because of the federal budget deficit, politicians are looking for any ideas that can save money for the federal government.

- **Proper messenger required.** Participants suggested that getting the topic of end of life on the national agenda requires the proper messenger. Currently, no one wants to discuss this topic. Raising the subject of end of life can't be done by politicians, clinicians, or the healthcare industry. It has to be led by a citizen/consumer voice. The best voice may be that of AARP, where members are caring for their parents. Another great candidate is the business community, because they have a lot vested in this (as Dr. Pawlecki showed) whether they realize it or not.

- **Systemic alignment.** Greater alignment is required throughout the healthcare system. This can be driven by bundled payment and also possibly through accountable care organizations.

## CONCLUSIONS

This conference touched on a broad range of topics related to end of life. Among the key conclusions are:

- **A reexamination is needed in how end of life is thought about and how care is delivered.** Our society does not like to talk about the end of life. The subject is taboo and is not discussed. But if we talk about and think about the end of life, our society would likely structure our healthcare system differently. The current healthcare delivery system is focused on acute events and infections. Yet today, people grow old with chronic diseases. A different mindset is required, which will undoubtedly result in a different type of healthcare delivery system.
- **Rethinking end of life requires a change in our culture, which requires different stories.** Despite the inevitability of death, our culture denies death and we do everything possible to avoid it. We glorify stories of the healthcare system miraculously extending a person's life. (This culture is epitomized with the quote of a hospital CEO who said, "If you come to our hospital, we won't let you die.")  
  
Our culture lacks stories of positive end-of-life experiences where people state their end-of-life wishes, are surrounded by loved ones, are without pain, and die in dignity. Our society needs different stories to change how our culture views death.
- **End-of-life experiences should be based on a person's values and priorities.** Most people want to die at home, in the presence of loved ones, in the absence of pain. However, this is

often not what occurs. Individuals are often in hospitals and receive intensive treatment in their final days.

A major theme of this conference was the need to have conversations with individuals to understand their personal wishes. It is important to have such conversations in advance of a crisis and to document the individual's wishes. Several initiatives are underway focused on conversations with patients.

- **Unnecessary, costly care is often provided at the end of life.** Among Medicare beneficiaries, approximately 27% of all spending occurs in the last year of life, a level that is unchanged over the past few decades (granted, we only know someone's last year or days of life after the fact). Much of the spending that occurs is for hospitalization, readmission, time in an ICU, and intensive treatment such as chemotherapy—often in the last two weeks of life. Multiple presenters also described “futile” care where intensive treatment is provided (often at significant cost) despite no possibility that the patient will improve.

In addition, several presenters shared data about the enormous variability in the intensity of services provided at the end of life, as well as variability in the cost of these services. This variability reflects differing practices, processes, and cultures in different healthcare environments. It is also consistent with the variability that exists throughout the healthcare system. More research is needed to better understand the underlying causes for the variability in end-of-life care.

- **Better coordination is needed for end-of-life care.** Multiple presenters described the highly fragmented care that is provided for individuals at the end of life. Lack of coordination and lack of alignment of incentives decreases the satisfaction of patients and families, and increases the costs of caring for patients.

This is reflected in high readmission rates upon discharge from an acute care hospital to a skilled nursing facility or a nursing home.

Many participants believe that changes in provider incentives (e.g., bundled payment) will force providers, particularly hospitals, to improve the coordination of care. Formation of accountable care organizations (ACOs) and quality improvement organizations (QIOs) and reporting on quality and readmission are other ways to drive better care coordination.

- **Much is working in improving end-of-life care.** Throughout the conference, multiple presenters shared examples of programs that are improving end-of-life care. Most notably, the availability and use of palliative care and hospice services has grown tremendous in the past three decades.

In the past decade, the VA has transformed the palliative care services offered to veterans across the country. POLST, developed in Oregon and now in use in eight states across the country (with more to follow), has been successful in getting individuals to document the types of medical interventions they would like to receive.

Aetna's Compassionate Care<sup>SM</sup> program is a successful phone-based case-management program that has improved the end-of-life experience for terminally ill members, improved the satisfaction of family members, and dramatically reduced the use of healthcare resources.

Project Compassion has helped build capacity in communities to deliver end-of-life programs. Both Closure and the Conversation Project are initiatives focused on training clinicians and caregivers to initiate important conversations with individuals at the end of life. Pitney Bowes also has a program for employees that encourages them to have conver-

sations with loved ones about important topics, such as end-of-life wishes.

- **Caregivers and communities are critical parts of end-of-life care that cannot be overlooked.** Millions of Americans are currently caregivers, investing significant time and money and even compromising their own health. As the demographics of the country change, more individuals need care and there will be fewer individuals to provide it, putting even more of a burden on caregivers.

Thinking about the challenges associated with caregivers illustrates that the end of life is not a medical issue. It is a personal issue involving families and communities. Caregivers, communities, and families could all benefit from more resources and more focus on end-of-life issues.

- **Changing the culture and scaling successful end-of-life efforts requires policy changes.** Throughout this

conference, speakers and participants offered multiple policy considerations. These ranged from state-level policies to adopt POLST, to federal policies to preserve the hospice benefit. The National Hospice & Palliative Care Organization is supporting new care models and Dr. Ira Byock offered almost 20 policy considerations. Stuart Altman pondered whether voluntary programs would be adequate to curtail high levels of spending associated with the end of life, or whether legislation would be necessary to make certain programs mandatory.

Most participants believe politicians will be hesitant to create any restrictive policies related to receiving care, even if futile, at the end of life. For policies to change there needs to be a grassroots effort led by an advocacy organization such as AARP.



*Stuart Altman, Council and Forum Chair*

The primary mission of the Council is to provide an independent, non-partisan deliberative body of recognized experts to identify critical issues generated by health system change, analyze the economic impact of such changes, and disseminate findings to national policy makers, health services researchers, industry leaders, and the general public.

The mission of the Health Industry Forum is to develop practical, actionable, market-oriented strategies to improve the quality and value of the U.S. healthcare system. To support this mission, the Forum sponsors independent, objective policy analysis, and provides a range of neutral venues where healthcare leaders and other stakeholders work together to develop strategies and solutions.

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*Speaker presentations can be found at the Council website. The authors wish to thank Michael Doonan, Rob Mechanic, and Mark Krasnow of BullsEye Resources, for their contributions to this work, and Sarah Ferguson, who was instrumental in coordinating the Princeton Conference.*