

# Transitioning care at the end of life: Quality measures and the Affordable Care Act

“When the human dimension of dying is nurtured, for many the transition from life can become as profound, intimate, and precious as the miracle of birth” – Ira Byock, *Dying Well* (1997)

## INTRODUCTION

The inevitability of mortality is perhaps one of the more irreconcilable truths of our ever-advancing civilization. In the world of health care — whether you are a clinician, a caregiver, or a patient — some of the most important decisions we will make will be ones concerning end-of-life care. There is likely no other period of life that more essentially explores questions of how we want to live our lives; yet, no other time more fraught with ethical dilemmas, ambiguous language, stigma, confused intentions, “what-ifs,” and speculations of “what could have been.” Too often, patients and their caregivers find themselves in a state of chaos, walking the tightrope during a time there is most desperately the need for firm footing and the security of familiar resources to guide us through the journey of dying. These are not easy conversations, and these are conversations that largely are not happening with the right people, at the right place, at the right time. In America, an aging population, with rising life expectancy coupled with the advances of biomedicine and technology, is now facing a new frontier: chronic illness. Compared to even mere decades ago, today’s elderly are more likely to die from an accumulation of various conditions — side effects of old age — rather than singular instances of acute health

crises. Patients and health care providers alike have only recently begun to learn what it means to manage not only chronic care but also quality of living at the end of life.

With these changing goals of care and an intensified spotlight on quality of care, palliative medicine and hospice have emerged as prime targets for ways we can improve how we care for the whole patient rather than merely treat a collection of conditions and diseases. Evidence indicates that our model of health care lags far behind our current standards for patient care; medical training that once prized acute care above all is now falling behind, leaving health care providers grasping for the right tools and leaving patients grappling with disjointed care at the end of life (Rifkin 2014). Perhaps a fundamental challenge is defining the nebulous “end-of-life” period. In the vast majority of cases, there is no distinct line in the sand marking the beginning of the “end of life”; rather, it is a gradual process that likewise calls for a gradual transition to the appropriate care. Patients today, however, often find themselves suddenly passed off to an unfamiliar hospice team within the last couple of weeks, even days, of life — a shocking, uncomfortable, and confusing transition that is further intensified by the stresses of poor health. These situations usually reflect not a series of shortcomings in individual health care providers, but rather a systemic failing in the delivery of care by an institution that fosters misguided attitudes toward chronic and end-of-life care. This paper seeks to address this landscape of end-of-life care, first by looking toward anthropological notions of death and quality of care, then examining the Patient Protection and Affordable Care Act of 2010 (ACA) and its standards on quality and quality reporting. Lastly, the costs of end-of-life care will be discussed in relation to quality of care, particularly in the context of the ACA.

Bluntly, the elephant in the room is death and dying, and because of the historically poor transition to and incompetent use of palliative and hospice care, these otherwise invaluable

resources have also come to share the stigma and blame as we continue to turn our heads from the inevitable. The Patient Protection and Affordable Care Act was passed in 2010 in effort to begin addressing some of these institutional shortcomings in our health care system. The Affordable Care Act is an ambitious document with many objectives, but it notably aims to expand health insurance, consolidate care, improve quality of care by mandating quality reporting, and reduce costs of care. It also furnished the establishment of an Innovation Center under the Centers for Medicare and Medicaid Services (CMS), laying the groundwork for experimental health care models. One such initiative is the Medicare Care Choices Model (MCCM), which seeks to evaluate the integration of palliative care with curative-intent treatment in a limited number of select hospice providers across the country. Programs such as the MCCM are strong steps toward a health care system that prioritizes continuity of care and quality of life at every step of the patient's illness experience.

Another challenge, however, arises from the discourse on quality of care: how do we measure quality? Many quality measures discussed in this paper pertain to hospitals and other institutions, which tend to have the most developed quality measures of the different forms of health care delivery centers. Current CMS hospital quality measures rely heavily on mortality rates, readmission rates, and complication rates — measures that, while easily quantifiable, fail to take into account quality of doctor-patient conversations, integration of care across specialties, end-of-life planning, and other aspects of holistic patient care. What results is a “quality” report that more often measures quantity than quality of life. While the reinvigorated focus on preventative care is laudable, our current quality measures provide virtually no incentives for supportive care and other medical decisions that are not specifically geared toward extending life. Beyond evaluations of hospitals, health care quality measures for patients are equally scant.

While the scope of end-of-life care extends to practically all health conditions and combinations of conditions, this paper focuses predominantly on cancer as both a chronic and acute illness and a model for discussing the strengths and weaknesses of the American health care system and our society's attitudes toward illness, medicine, and dying.

Of the Affordable Care Act's three guiding principles — expansion of health care coverage, improvement in quality of care, and reduction in health care spending — the former two are thought to go hand in hand with the last. This paper's analysis of quality of end-of-life care thus also discusses the currently disproportionately high rate of spending for care at the end of life. Costs incurred by the sickest five percent of Medicare beneficiaries account for nearly half of total Medicare spending (Congressional Budget Office 2005). Further analyses have revealed common characteristics of these high-cost patients, who are significantly more likely to be elderly, to have chronic conditions, and to have one or more emergency department visits and hospital admissions per year. Studies have shown palliative care services to not only increase patient comfort and extend life, but also slash costs traditionally associated with acute health care measures common at the end of life. Hospices, which are designed to care for patients with prognoses of 6 months or shorter, also dramatically reduce health expenditures at the end of life for many patients while providing the option to die at home rather than in intensive care units, as so many patients fear and as too many patients do. These are measures that require the thoughtful and intentional advance care planning that is traditionally lacking from Western attitudes toward medicine and health care.

The transitional challenges plaguing health care providers, caregivers, and patients at the end of life ultimately can be traced back to a number of shortcomings in institutional practices and cultural attitudes that result in both substandard quality of life and exorbitant costs of care.

Better and earlier palliative and hospice services hold great potential to not only reduce health care spending at the end of life but also bridge these challenging transitions and guide physicians and patients in opening the conversations necessary for making decisions that truly serve the patients' best and autonomous interests.

## LANDSCAPE OF CHRONIC AND END-OF-LIFE CARE

As it stands, the American health care system is one that is strongly geared toward providing acute treatments for urgent conditions, resulting in short bursts of high-cost, high-intensity care rather than longer-term management of care. This approach is especially inappropriate for two groups of patients — those who are chronically ill and those at the end of life — for whom proper advanced planning and long-term management of care is critical for good quality of life and for patients' wishes to be known and respected. Yet, studies have shown that while most chronically ill patients express a preference to die at home rather than in a hospital, the majority of these patients end up dying in a hospital anyway (Goodman 2011). Furthermore, chronically ill patients spend on average around 11 days in a hospital in the last six months of life, while cancer patients spend on average 5.1 days in a hospital within just the very last month of life (Goodman 2011, Goodman 2010). These trends are symptomatic of a larger underlying problem in our health care system; we are failing our chronically and terminally ill patients — not by failing to offer enough aggressive medicine and new technologies, but by failing to acknowledge and address the realities of necessary symptom management and advance care planning. A recent report by the Institute of Medicine titled “Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,” notes the timeliness of health care reform — such as under the Patient Protection and Affordable Care Act of 2010 —

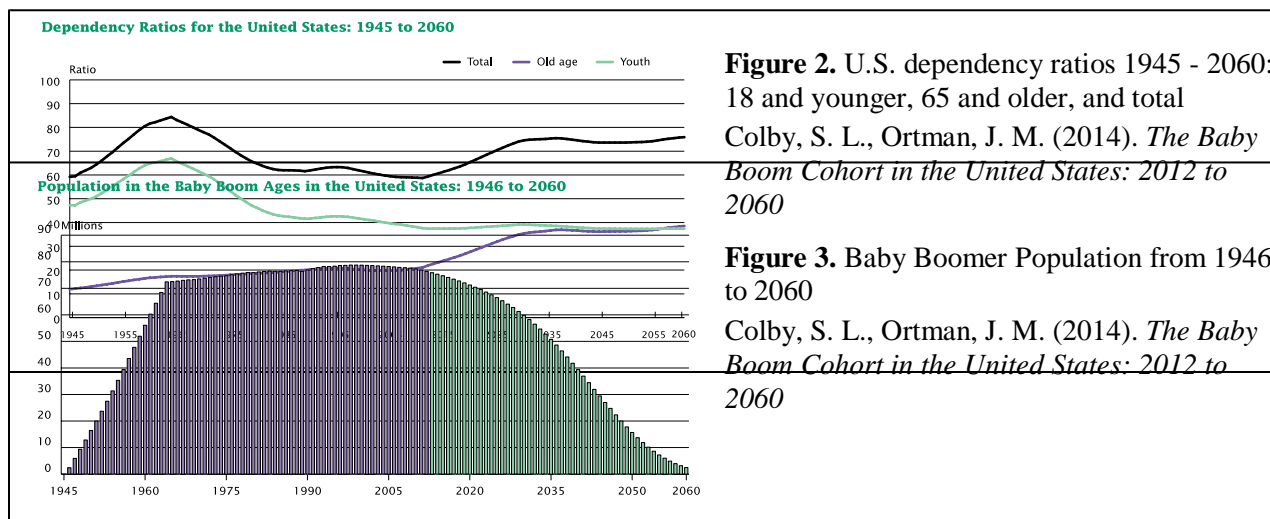
and the need for better integration and consolidation of care, advance care planning, palliative and hospice services, and professional education and development in these areas (IOM 2014).

As compared to a century ago, Americans are living longer and with a greater complexity of chronic illnesses; likewise, health care, death, and dying are becoming increasingly medical-

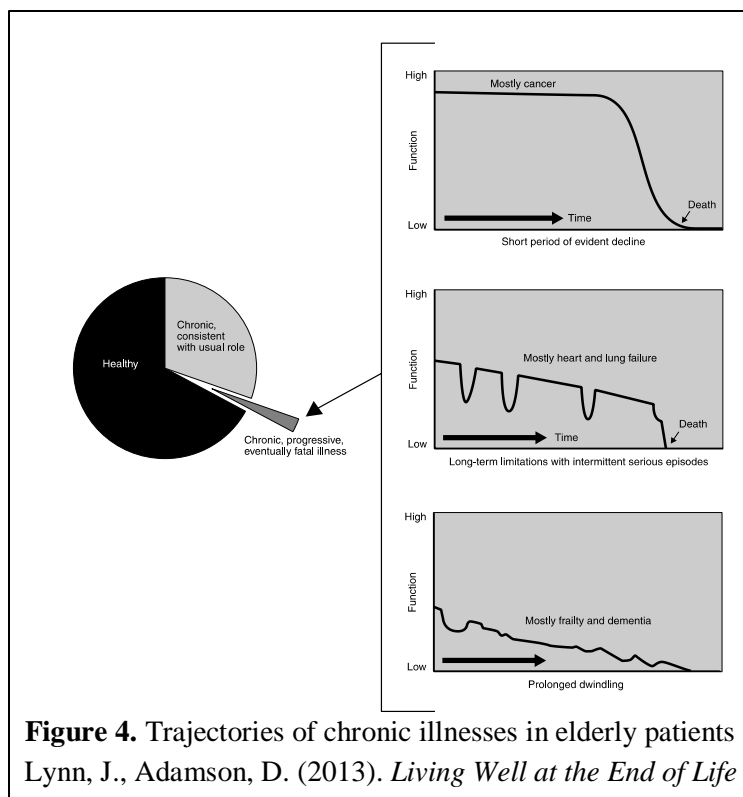
A Century of Change (6)		
	1900	2000
Life expectancy	47 years	75 years
Usual place of death	home	hospital
Most medical expenses	paid by family	paid by Medicare
Disability before death	usually not much	2 years, on average

**Figure 1.** Changes in health care between 1900 and 2000.  
Lynn, J., Adamson, D. M. (2013). *Living Well at the End of Life*

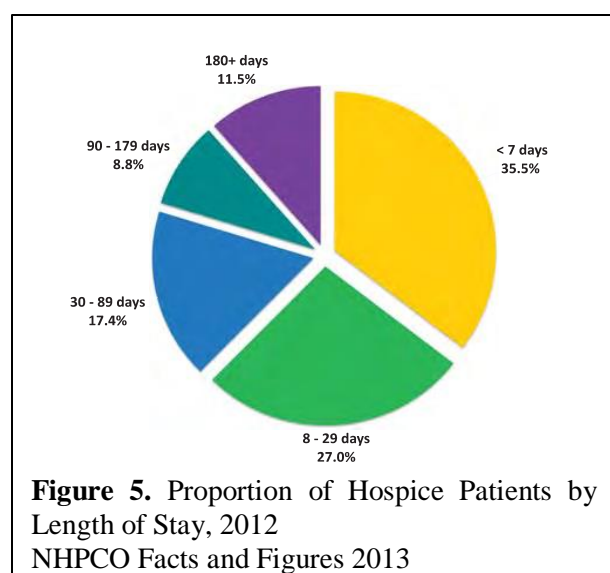
ized. (Figure 1) With an aging population of Baby Boomers accounting for an increasing proportion of elderly individuals in our society, as well as a slow but accelerating mortality rate among Baby Boomers, our health care system must adjust to the mounting significance of chronic illness management and end-of-life care. (Figures 2, 3)



Palliative care and hospice thus emerge in this setting as services proven to not only reduce costs associated with end-of-life care but also provide care that allows patients to live their lives with the greatest quality possible. In the common trajectories of chronic illnesses, advance planning can help patients and their caregivers prepare for patterns of decline in health and come to terms with realistic goals of care. (Figure 4)



Timely hospice enrollment in each of these cases offers patients and their caregivers palliative and supportive resources in the settings of their own homes and can significantly ease the burden of transitioning and consolidating care at the end of life. Nevertheless, hospice services are



considerably underused, despite gaining traction over the past few decades. While the maximum benefit derived from hospice has been shown to arise from stays of 80 to 90 days, the average cancer patient spends merely 8.7 days in hospice at the end of life — scarcely enough time to even get acquainted with the hospice team and its services, much

less derive improved quality of life (The debate in hospice care 2008; Goodman 2010). (Figure 5) Furthermore, a study by Murillo et al. found chemotherapy administration rates to be as high as 43 percent in the last month of life and 20 percent within the last two weeks of life — rates that the study authors suggested were elevated by the increased availability of new chemotherapeutic agents (Murillo 2006). Non-palliative chemotherapy so close to the end of life is largely thought to be medically futile, only incurring unnecessary costs and delaying hospice enrollment, cutting short time that the patient may need to properly come to terms with death and dying. In surgeon and MacArthur Fellow Atul Gawande’s *Being Mortal*, he observes that “arriving at an acceptance of one’s mortality and a clear understanding of the limits and the possibilities of medicine is a process, not an epiphany” (Gawande 2014). However, because the Medicare Hospice Benefit currently requires cessation of curative-intent treatment as a prerequisite for hospice enrollment, patients and clinicians alike are often unwilling to begin exploring alternative options and outcomes, exacerbating physician and patient attitudes that may favor continuing to “fight” the cancer, particularly in light of new and improved medicines and technologies and when the alternative of hospice enrollment is culturally framed as “surrender.”

American attitudes toward health and biomedicine are deeply ensconced in a culture of “cure,” when the reality is that our aging population and our new life-prolonging technologies call for better medical planning and long-term management of care. Anthropological theories on illness, death, and dying attempt to elicit the multiple dimensions of the illness experience and what it means to have a “good death” amidst — and perhaps despite — the latest and greatest biomedical technologies. Much of the modern attitudes toward health and medicine are described by the philosopher Michel Foucault as a product of the “medical gaze,” a term he coined in *The Birth of the Clinic* to describe the dehumanizing phenomenon of the medical separation of the



patient's body and bodily conditions from the patient as a whole person (Foucault 1975). In essence, the medical gaze transforms the patient in the clinic into no more than an embodiment of his/her illness. Perhaps the most problematic outcome of the medical gaze is the loss of the ability to appreciate the patient's illness experience and the value of quality of life. Particularly in end-of-life matters, inability to prioritize quality of life over unrealistic curative goals can often lead to painful and undignified deaths and traumatic experiences by patients, their families, and their medical caregivers. Sociologist Stefan Timmermans describes the modern attitude toward death as one that stages physicians as "death brokers" who are tasked with rendering deaths "culturally appropriate" — which, in our society, has come to mean the "seclusion and professional management of death" and the determination of causes of death and delaying such causes (Timmermans 2005). The result of these attitudes, according to sociologist Zygmunt Bauman, is a professionalization of the dying process. Ironically, "fighting the causes of dying turns into the meaning of life" (Bauman 1992). In recent decades, however, these "death brokering" strategies have been strongly and increasingly challenged by two movements within the medical field — hospice and right-to-die — which have largely shifted the goals of medicine toward providing holistic, patient-centered care that balances disease-directed treatment with goals of comfort and support. Both movements aim to restore autonomy to patients and their caregivers by de-medicalizing the process of dying and offering patients the opportunity for a "good death." Several scholars, including Margaret Lock, Philippe Aries, and Susan Sontag, have described modern notions of a "good death" as a pain-free death that takes place in one's own home, and conversely, an adverse one as one that is painful or prolonged to no benefit (Lock 2002, Aries 1974, Sontag 1978).

Hospice has come to embody the “good death,” almost to the point of institutionalizing the concept, involving “aggressive symptom management and attention to the religious, social, and psychological needs of the dying and their loved ones”— and as Timmermans critiques, all to the ends of achieving the “normative goal of accepting impending death” (Timmermans 2010). Timmermans appears, however, to confuse the goals of hospice; acceptance of human mortality is a byproduct of holistic and quality-centered care, not the reverse. Furthermore, hospice’s institutionalization and “normalization” of the “good death” do not necessarily detract from its values of holistic end-of-life care, as Timmermans implies. For many patients and their caregivers, the regimented and clear goals of hospice offer a sense of security and support during an otherwise frightening and unfamiliar experience. Poor planning, or lack of planning altogether, often results in fragmented care, unrealistic goals of care, and ultimately, chaos and tension as patients and their caregivers and physicians struggle to meet on decisions that best uphold the bioethical principles of patient autonomy, beneficence, non-maleficence, and just access to due care.

Increasing evidence indicates the benefits of timely hospice and palliative care extend beyond improving comfort and support to even significantly extending life (Temel 2010). Nevertheless, numerous cultural, economic, and political obstacles permeate and shape our ability to understand and accept palliative care, hospice, and other medical treatments not geared toward an intent to “cure.” In essence, these services lack the cultural authority that the notion of “cure” commands; they appear to require some degree of negotiation and reconciliation with “conventional” curative-intent treatments, but only superficially so. A somewhat radical view is that even curative-intent treatments are palliative in nature. In a Kantian justification of this claim, if we take quality of life to be the ends — the Categorical Imperative or moral law of

Medicine — and medical treatments and technologies to be the means, then it logically follows that the value of medicine lies in its ability to provide good quality of life. Both what we classify to be “Palliative” and “Curative” treatments, thus, are in theory limited by the condition of improving the patient’s quality of life, or in other words, palliating the patient. When a treatment undermines the universal end of maintaining or improving quality of life, it fails to be morally acceptable. Given this understanding of medical ethics, Bauman’s observation that modern medicine has turned “fighting the causes of dying... into the meaning of life” is concerning and reveals a more deep-rooted malady in our society’s attitudes toward medicine (Bauman 1992).

An archetypal example of this problem manifests in the current landscape of America’s attitude toward cancer. Since former President Richard Nixon declared a War on Cancer in 1971 with the enactment of the National Cancer Act, battle metaphors have resonated throughout discourses on cancer, glorifying cancer patients and survivors as “fighters” and “veterans” and inviting the American people to join and support the war efforts. Rose-colored awareness campaigns bloomed across the country, where cancer survivors are paraded, figuratively and literally, around town as heroes of war. Despite well-meaning intentions, however, the elaborate language and drawn out metaphors belie and marginalize the experiences of many patients who opt for less aggressive treatments and those who have poor, less treatable prognoses. While recent years have brought increased awareness among the medical community to the inappropriate use of battle metaphors in describing cancer treatment, patients still frequently rely on these metaphors as crutches and coping mechanisms for finding hope and making sense of their diagnoses, particularly in the absence of other supportive and advance planning services. Battle metaphors also make for catchy sound bites that are further propagated by mass media and advertising, particularly by many non-professional cancer foundations such as Susan G. Komen

and the V Foundation for Cancer Research. The illusion of cancer as a “war” with a victory of cure on the horizon is particularly damaging as it promotes unrealistic goals of care that detract from patients’ and caregivers’ abilities to come to terms with the realities of long-term care and of dying.

At around the same time America was sold into this metaphorical war, Talcott Parsons coined the concept of the “sick role,” outlining “the rights and obligations of the sick person in society, describing clearly what illness behavior is acceptable to society and what rewards the ill person can expect from conforming to that behavior” (Haigh, 1993). Namely, our society expects the “sick” individual to take responsibility for his/her cure and recovery and provides exemption from certain societal duties in order to fully pursue this goal. The sick role, while useful in cases of acute illness, has been heavily criticized when applied to chronic and incurable diseases — as in many cases of cancer and other end-of-life conditions — as it fails patients for whom a quick recovery is not a feasible option. Thus in recent years, an alternative “dying role” has emerged to better encompass terminally and chronically ill patients for whom the sick role is inappropriate. Sociologist and social worker Debra Parker-Oliver argues that for these patients, the “concept of the ‘sick role’ and the social institutions that provide legitimization for it fail, both from the perspective of the dying individual and from the perspective of the social institution” (Parker-Oliver 1999-2000).

This lose-lose relationship between the sick role and the terminal or incurable cancer patient highlights how battle metaphors — for example, the V Foundation’s slogan: “Don’t give up.... Don’t ever give up!” — not only fail those they are intended to serve but also effect stigma against death and dying. Parker-Oliver further proposes that the transition from the sick role to the dying role is both symbolically and practically mediated by hospice enrollment. Hospice as

an institution is designed to legitimize the dying role, as hospice teams provide patients and caregivers with a full repertoire of holistic services to maximize quality of life and help renegotiate personal meaning from the biological event of death and dying. Nevertheless, stigma against the discourses on death and dying remains a major hurdle in providing timely and accessible palliative and hospice care (Detering 2010). These biases are neither entirely personal, nor are they entirely social or cultural. Macro-level socioeconomic and political forces as well as microcontexts that mediate our social and personal processes come together to form a “local moral world,” according to psychiatrist and medical anthropologist Arthur Kleinman (Kleinman 1992). Amidst the broad human conditions of illness and death, it is our local moral world that shapes our specific navigation of and our relationship with these universal concepts. Using Kleinman’s theory, understanding patients’ local moral worlds may go a long way in eliciting their illness experiences and reconnecting with what is at stake for a sick or dying individual in our society.

Take Jenny, for example, a practicing psychologist in her late fifties who had been diagnosed with stage IV non-small-cell lung cancer six years earlier. Jenny had approached Diane Meier, a physician and leader in geriatric and palliative medicine who later published this encounter in an issue of the journal *Health Affairs: Narrative Matters* (Meier 2014). Over the past six years, Jenny, like many other patients, learned to live with cancer as a chronic disease. She had seen remissions, recurrences, and progressions, and she was attached and grateful to her oncologist, who always had a new approach to try. Considering Jenny’s well appearance, Meier wondered why Jenny had sought a consultation. Jenny explained that despite her oncologist’s superb management of her cancer care, she often felt as if he were unwilling to talk her through the “what-ifs” of the disease — questions regarding what she should expect at the end of life.

Meier was happy to address Jenny's concerns, and for over a year, Jenny continued to see both physicians, until her condition began to deteriorate after the discovery of a metastasis to her brain. Her oncologist suggested intrathecal chemotherapy to administer the treatment directly to the tumor mass in the brain, and Jenny wanted Meier's opinion. Meier, who was unfamiliar with the data on the treatment, offered to ask Jenny's oncologist about the procedure and help come up with an appropriate plan. During their call, Meier asked:

"What are you hoping to accomplish with this treatment?" After a brief pause, he spoke.

"It won't help her." [Meier] struggled for a response. "Would you want me to encourage her to go ahead with it anyway?" [she] asked, finally. After another pause, this one longer and more awkward than the last, he said, "I don't want Jenny to think I'm abandoning her."

Themes of patient abandonment echo throughout the reflections of many clinicians, particularly of those who have built long and deep relationships with their patients. From the perspective of Jenny's oncologist, situated in his local moral world, what he felt was at stake was his fidelity to Jenny as a medical caregiver. For Jenny, what was at stake was her ability to understand and plan for the end of her life.

Over the course of the conversation, Jenny's oncologist had a change of mind and decided against recommending the chemotherapy, and Jenny went on to receive home hospice care. Toward the end of her life, as she prepared to die, Jenny wished to see her oncologist one last time. Her oncologist made his first-ever home visit, and Jenny was able to express her gratitude for his good care over so many years. Shortly following their reunion, Jenny died.

## QUALITY MEASURES IN HEALTH CARE AND THE AFFORDABLE CARE ACT

Patients as educated about and at peace with their conditions as Jenny was and deaths that are as well planned as hers were remain rare, despite increased accessibility and utilization of hospice services. Quantitative studies have revealed trends of fewer deaths taking place in hospitals, but also increased intensity of care, including days spent in an intensive care unit, during the last six months of life (Goodman 2011). Meanwhile, increase in total hospice enrollment has been coupled with stagnation of median length of stay at around 18 to 19 days, indicating that patients are still enrolling too late to fully derive value from hospice (NHPCO 2012). The piling studies and statistics surrounding our health care system largely seek to address two central questions: Are Americans receiving quality health care? And how do we improve the quality of medical care at a reasonable cost? In response to the first question, most Americans would answer “no.” The percentage of Americans who view the state of health care across the country as “good” or “excellent” has hovered between 21 and 30 percent from 2002 to 2009, with a boost to 38 percent in 2010 and a high of 41 percent in 2013 (Newport 2013). In 2010, the year of the 8-point rise, the Patient Protection and Affordable Care Act was signed into action, laying out 906 pages of new and amended health care laws in hopes of providing more people with better and more affordable care. Notably, the ACA is determined to establish rigorous standards of quality, even while expanding coverage and cutting health care expenditures. A mechanism by which the ACA hopes to accomplish this goal is reimbursement-based quality reporting that merges horizontal standardization of measures across the private and public sectors with vertical alignment to capture quality measures at three main levels of health care delivery: the institution/facility, the individual clinician, and the patient population at large (Conway 2013).

One fundamental quandary that arises from discussions on quality of care and reporting measures is that “quality” is a relatively subjective term and holds a wide range of different meanings for different people. The ACA uses the word “quality” 563 times from start to end; yet, at the time the act was signed into law, it provided minimal to no definition of quality. Even in Section 3013, “Quality Measure Development,” the term “quality measurement” is defined loosely as “a standard for measuring the performance and improvement of population health or of health plans, providers of services, and other clinicians in the delivery of health care services” (ACA 2010). What forms these nebulous “standards,” may take, however, are described in the text of the ACA as to be developed by the Human and Health Services Secretary at a later date. In fact, the phrase “the Secretary shall establish” appears 109 times throughout the ACA, and “the Secretary shall develop” appears 37 times, excluding other variants of the phrase, leaving a big question mark even on the final, authorized act. These quality measures have largely been defined as of now, though certain measures have been contested and criticized for not truly capturing dimensions that sturdily predict patient outcomes and quality of life. As the ACA has only recently begun to unfold relatively recently, the efficacy of the determined quality measures has not yet been thoroughly assessed, nor has the impact of these measures on quality of care yet been defined. Given the overwhelming scale of the ACA and all of its unknowns, experts have been reluctant to conjecture exactly how the ACA will unfold. Ripples from these reforms, however, are beginning to pan out now, a year after the ACA’s first open enrollment period. The New York Times published an analysis gauging the impact of this first cycle, comparing how the ACA, so far, is stacking up against its stated objectives (Figure 6).



Cutting straight to the chase: “Is the Affordable Care Act Working?” (NYT 2014)

Broadly speaking, yes, according to data showing improvements in the percentage of uninsured Americans and the availability and costs of health insurance. But what about the quality of health care? “Of all the pledges made for the Affordable Care Act,” the *Times* reported, “... perhaps the loftiest and hardest to demonstrate was that it would make the

nation healthier” (NYT 2014). Indeed, most experts say that it is too soon to tell whether health across the nation is improving or not. While certain health benefits have been demonstrated in the young, who can now remain under their parents’ insurance plans until they turn 26, very little change has been seen beyond this age group. One significant change among older individuals, however, is an increase in screenings for colon cancer, which is now covered by insurance under the ACA at not cost to patients, along with other preventative screenings.

How these preliminary findings will translate as the ACA more fully unfolds is unknown, though results thus far are conservatively encouraging. In the realm of health outcomes, however, the scarcity of data leaves much to be explored in terms of what we might expect in coming years. Despite ambiguous language surrounding quality measures and quality reporting, certain provisions and structures of the act provide limited insights as to where the ACA places its values. Under Section 2701 of the ACA, a subcommittee representing a partnership between CMS and the Agency for Healthcare Research Quality drew up a “Core Set of Health Care

- 1 **Has the percentage of uninsured people been reduced?**  
Yes, the number of uninsured has fallen significantly.
- 2 **Has insurance under the law been affordable?**  
For many, yes, but not for all.
- 3 **Did the Affordable Care Act improve health outcomes?**  
Data remains sparse except for one group, the young.
- 4 **Will the online exchanges work better this year than last?**  
Most experts expect they will, but they will be tested by new challenges.
- 5 **Has the health care industry been helped or hurt by the law?**  
The law mostly helped, by providing new paying patients and insurance customers.
- 6 **How has the expansion of Medicaid fared?**  
Twenty-three states have opposed expansion, though several of them are reconsidering.
- 7 **Has the law contributed to a slowdown in health care spending?**  
Perhaps, but mainly around the edges.

**Figure 6.** “Is the Affordable Care Act Working?”  
*The New York Times* (2014)

Quality Measures for Adults Enrolled in Medicaid.” Unfortunately, the Medicaid Adult Core Set of 26 health measures falls disappointingly short of its potential, in particular, to address the many social and discursive aspects of chronic and terminal illness. As shown in Figure 7, the 26

Abbreviation	NQF #	Measure Steward	Measure Name
FVA	0039	NCQA	Flu Vaccinations for Adults Ages 18 to 64
ABA	NA	NCQA	Adult Body Mass Index Assessment
BCS	0031	NCQA	Breast Cancer Screening
CCS	0032	NCQA	Cervical Cancer Screening
MCS	0027	NCQA	Medical Assistance With Smoking and Tobacco Use Cessation
CDF	0418	CMS	Screening for Clinical Depression and Follow-Up Plan
PCR	NA	NCQA	Plan All-Cause Readmission Rate
PQI01	0272	AHRQ	PQI 01: Diabetes Short-Term Complications Admission Rate
PQI05	0275	AHRQ	PQI 05: COPD and Asthma in Older Adults Admission Rate
PQI08	0277	AHRQ	PQI 08: Heart Failure Admission Rate
PQI15	0283	AHRQ	PQI 15: Asthma in Younger Adults Admission Rate
CHL	0033	NCQA	Chlamydia Screening in Women Ages 21 to 24
FUH	0576	NCQA	Follow-Up After Hospitalization for Mental Illness
PC01	0469	TJC	PC-01: Elective Delivery
PC03	0476	TJC	PC-03: Antenatal Steroids
HMV	2082	HRSA	HIV Viral Load Suppression
CBP	0018	NCQA	Controlling High Blood Pressure
LDL	0063	NCQA	Comprehensive Diabetes Care: LDL-C Screening
HA1C	0057	NCQA	Comprehensive Diabetes Care: Hemoglobin A1c Testing
AMM	0105	NCQA	Antidepressant Medication Management
SAA	NA	NCQA	Adherence to Antipsychotics for Individuals with Schizophrenia
MPM	0021	NCQA	Annual Monitoring for Patients on Persistent Medications
CPA	0007	AHRQ & NCQA	CAHPS Health Plan Survey 5.0H – Adult Questionnaire
CTR	0648	AMA-PCPI	Care Transition – Transition Record Transmitted to Health Care Professional
IET	0004	NCQA	Initiation and Engagement of Alcohol and Other Drug Dependence Treatment
PPC	1391	NCQA	Postpartum Care Rate

**Figure 7.** 2014 Core Set of Health Care Quality Measures for Adults Enrolled in Medicaid  
Centers for Medicare and Medicaid Services

voluntary health measures set forth by the Medicaid Adult Core Set are strictly clinical, despite the known importance of other factors — care coordination and management, specific needs of the elderly and disabled, social determinants of health such as education and income — in determining clinical outcomes. Although these inadequacies are

noted by experts and health organizations in critiques that CMS gathered in the process of compiling the list of measures, these shortcomings persist, even in the updated 2014 Medicaid Adult Core Set (National Quality Forum 2013).

How, then, do these quality measures at the patient level relate to quality measures at the levels of the clinician and the larger institutions and health facilities? Where the patient health measures are lacking, standards of care implemented at the physician level may potentially compensate. Quality domains under the ACA’s Physician Quality Reporting System include: effective clinical care, patient safety, communication and care coordination, person and caregiver-centered experience and outcomes, efficiency and cost reduction, and

community/population health. While most measures fall under “effective clinical care,” the inclusion of quality measures based on improving communication and the patient experience hold potential to move American health care in an encouraging direction. CMS also provides further recommended measures for different specialties. For example, in the 2015 Potential Oncology/Hematology Preferred Measure Set, two “experience and outcomes”-based measures encourage physicians to work with their patients to quantify chemotherapy- or radiation-related pain and create plans of care to address the pain. Indeed, pain may be one of the most important quality measures in addressing health care in America. In a study of 90,000 participants, a Washington State University study found that 11.6 percent of respondents reported experiencing pain every day, with almost a third of people 60 or older experiencing persistent pain (Kennedy 2014). Pain as a quality measure encapsulates the many facets of care that accounts for the entire person and his/her social, cultural, and physiological health and experience. Pain as a quality measure is absent from the 2014 Medicaid Adult Core Set and is a major quality-of-life factor in chronic and end-of-life care.

On the level of health care delivery facilities — such as hospitals and clinics, long-term care facilities, and hospices — the ACA also mandates strict quality reporting, as well as pay-for-reporting and pay-for-performance incentives and penalties. For hospitals, quality measures include readmissions, mortality, and hospital-acquired conditions, among others, though the American Hospital Association has expressed concern that “certain quality measures in federal programs do not lead to better outcomes for patients or do not produce accurate performance results” (AHA 2014). Indeed, two core quality measures — 30-day readmission rates and the “gold standard” outcome of mortality rates — have been shown to be both uncorrelated with and poor indicators of hospital performance (Jha 2013, Krumholz 2013, Thomas 1999). 30-day

readmission rates paradoxically incentivize worse care in some cases and have thus been criticized to hold hospitals to a standard that is too narrowly tailored for the institution's purposes. Many hospitals, for example, are increasingly placing patients in an outpatient "observation" unit to avoid the risk of readmitting the same patient down the road — a practice that often leaves patients with hefty bills (Huffman 2013). And when a patient who has been admitted in the past 30 days shows up in the Emergency Department, some hospitals are even sending them home when clinically, their conditions warrant readmission (Jha 2013). While such behaviors do not represent those of most health care delivery centers, these quality standards fail by incentivizing poor practices in certain and limited medical settings.

Mortality rates even more fundamentally fail to capture quality of care, as it assumes and reinforces a culture of "cure" without consideration of quality-of-life and other end-of-life factors, such as patients' decisions to abstain from extreme life-sustaining measures. Mortality statistics fail to differentiate between a patient who has died due to shoddy care and a patient who has died by his/her autonomous, planned choice to withhold from invasive and extreme life-extending measures. Hospitals with higher rates of "do-not-resuscitate (DNR)" orders were found to likewise have higher mortality rates (Kelly 2014). This reflects not substandard care, but rather, a natural result of respecting certain end-of-life wishes of many patients. In effect, using mortality rates to measure hospital quality may de-incentivize the advance care planning that is critical in providing ethically responsible care for patients, especially those with chronic or terminal illnesses and those who are part of the aging Baby Boomer generation.

Beyond hospitals, other health care facilities like hospices and long-term care facilities are also required to submit quality reports. Unlike the preponderance of paternalistic medical quality indicators present at other levels of health care delivery, hospice quality reporting

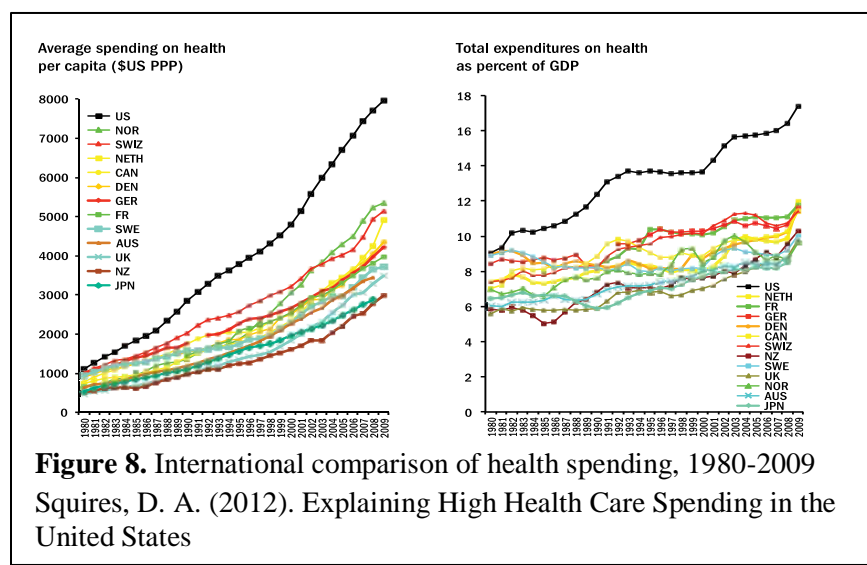
measures align with many of the practical and quality-of-life realities of end-of-life care. The Hospice Item Set specified by CMS includes measures primarily focused on assessing and addressing patient comfort, including pain and shortness of breath, side effects of pain medications, and the values and beliefs of patients and caregivers, should they wish to discuss them. Beginning in 2015, CMS, acting under the ACA, is further implementing a Consumer Assessment of Healthcare Providers and Systems (CAHPS) Hospice survey to calculate the outcome of the following quality measures: hospice team communication, getting timely care, treating family members with respect, providing emotional support, getting help for symptoms, information continuity, understanding the side effects of pain medication, and getting hospice care training (in the home setting of care only).

These measures accommodate patients in the “dying role” and respect the realities of that role, whereas at the polar opposite end of the spectrum, CMS hospital quality measures normalize every patient to the “sick role,” assuming “cure” to be the be-all and end-all of health care. The disconnect between hospital and hospice quality reporting measures reveals not necessarily a discrepancy in goals and attitudes of clinicians in these different settings, but rather an overarching failure of our culture and our health care system to integrate care across the continuum of health and illness and an inability to recognize cure and comfort as coexisting rather than mutually exclusive goals. Integrating these two goals of care requires mindful and well-coordinated delivery at the level of the clinician as well as the level of the larger health care system. Within recent years, medical training has been shifting to emphasize goals of treating the patient as a whole person beyond the illness, and palliative care and hospice are quickly gaining traction for their role in providing quality-centered, supportive care. At a fundamental level, clinicians care deeply about their patients and want the best for their patients. What the “best”

care means, however, can vary greatly from person to person. The role of the ACA should be to provide a specific yet comprehensive standard for how we can ethically define and deliver care and hold our systems of health care to standards that reflect the coexisting curative and comfort-directed goals of care.

## COSTS OF END-OF-LIFE CARE

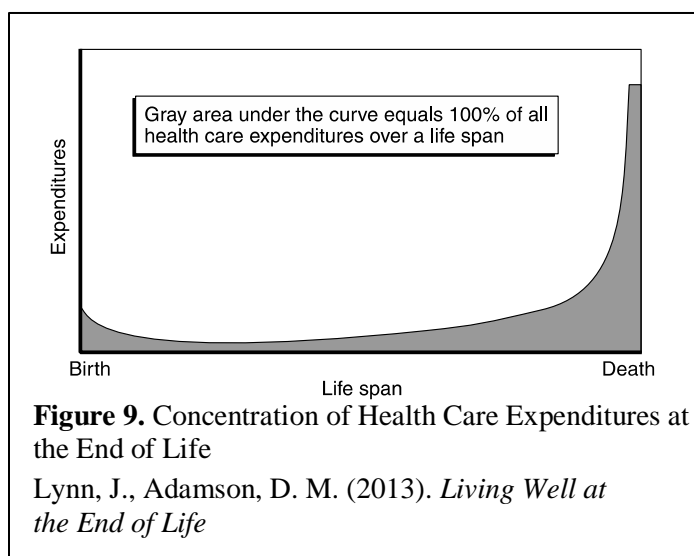
The ACA's goals of expanding coverage and improving quality of care across the board in theory will produce a side effect that aligns with its last objective: reducing health care spending. National health expenditures (NHE) account for 17.2 percent of the U.S. gross domestic product (GDP) as of 2012, according to a recent report by the Office of the Actuary at CMS. While the share is expected to rise to 19.3 percent by 2023, the NHE's rate of growth of around 1.1 percent faster than the growth of the GDP per year reflects a major slowdown from the rise between 1990 and 2008, during which health expenditures grew 2 percent faster than the GDP annually (Sisko 2014). Forecasts of national health expenditures as a percent of GDP have also slowed when compared to reports from 2008, prior to passage of the ACA (Sisko 2009).



Nevertheless, health care spending remains significantly higher in the U.S. — both per capita and as a percentage of GDP — than in other industrialized nations, while we continue to lag behind on many

measures of health care quality and outcomes (Squires 2012). (Figure 8) While incursion of costs is expected from expanding coverage under the ACA, many provisions aim to curb costs by generating competition among health plans, taxing high insurance premiums, and streamlining care to maximize timeliness and cost-effectiveness.

Over the lifespan of the average American, health care spendings tend to remain fairly level, with the exception of a small peak at birth and a major escalation at the end of life. (Figure 9) Indeed, end-of-life care remains one of the most perplexing challenges for not only clinicians but policy-makers as



well. When it comes to spending, the top five percent of highest-costing Medicare beneficiaries incurs nearly half of total Medicare expenditures, and the top quarter accounts for 85 percent of annual expenditures (Congressional Budget Office 2005). 14 percent of these patients will die within a year, and 40 percent will die within four years. Studies by the Dartmouth Atlas have found that approximately 90 percent of these deaths are associated with chronic illnesses. Patients with chronic illnesses within the last two years of their lives account for around 32 percent of total Medicare expenditures, with more than 25 percent of total health care costs concentrated within the last year of life (The Dartmouth Institute; Curtis 2012). For these patients, much of the cost can be attributed to unnecessary hospitalizations and medical interventions at the end of life. These interventions, as previously discussed, largely provide no medical benefit and in fact go against many patients' end-of-life wishes. Of patients who indicate

that they wish to die in the comfort of their homes, 55 percent end up dying in hospitals anyway, with around 20 percent of total deaths occurring in an intensive care unit (Curtis 2012).

Given these statistics, end-of-life care has recently become a popular target for health care reform for reasons related to both quality-of-life and cost. However, salvaging costs from ICU admissions and interventions has proved to be a seriously challenging task with large amounts of evidence pointing in opposite directions. Zhang et al. found that patients who reported having advance care conversations with their doctors had fewer interventions at the end of life, which in turn cut expenditures by around 36 percent, compared to patients who did not have end-of-life conversations with their doctors (Zhang 2009). Patients who had higher costs also died more poorly and reported worse quality of life within the last week of life. Other studies, however, have offered incongruous results suggesting no significant benefit from improved planning and advance conversations on end-of-life care. Notably, most negative studies date back to the early 1990s, while most positive studies were conducted within the last decade, perhaps indicating improvements in utilization of and adherence to patients' end-of-life wishes (Schneiderman 1994, SUPPORT 1995, Dannis 1991, Zhang 2009, Wright 2008). In one of the largest randomized trials studying end-of-life decision-making and use of extreme life-prolonging measures, the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) in 1991 found no reduction in use of costly life-prolonging interventions, and likewise no improvement in patient quality of death, when physicians were provided with accurate information on prognosis, patient preferences, and resources to facilitate palliative care and advance planning (SUPPORT 1991). Recent studies, however, have strongly indicated that advance care planning, palliative care services, and hospice concomitantly slash health expenditures and allow patients to maintain better quality of life at the end of life.



Data from the Organization for Economic Cooperation and Development (OECD) indicates that the U.S. spends \$2,180/day per acute care inpatient — nearly double that of the next highest OECD nation (Frogner 2006). For the most part, use of inpatient life-sustaining treatments at the end of life has been found to be rather cost-ineffective. A common measure of the cost-effectiveness of a medical intervention is the quality-adjusted life year (QALY), which weights health-related quality of life in a year of increased survival to generate a value between 0 and 1, with 0 indicating death and 1 indicating optimal quality of health. Among the SUPPORT cohort, the cost-effectiveness of mechanical ventilation was found to decrease with increasing risk of mortality, with costs averaging \$110,000 per QALY among patients with under a 50% chance of 2-month survival (Luce 2002). A more recent study by Brooks et al. of Surveillance, Epidemiology, and End Results (SEER) data on Medicare patients with advanced cancer shows acute hospital care to be the largest driver of regional spending, accounting for 67 percent of spending variation and 48 percent of total spending (Brooks 2014). Furthermore, hospice use was inversely related to total medical spending, suggesting that hospice may in some cases substitute for other more costly and ineffective forms of health care.

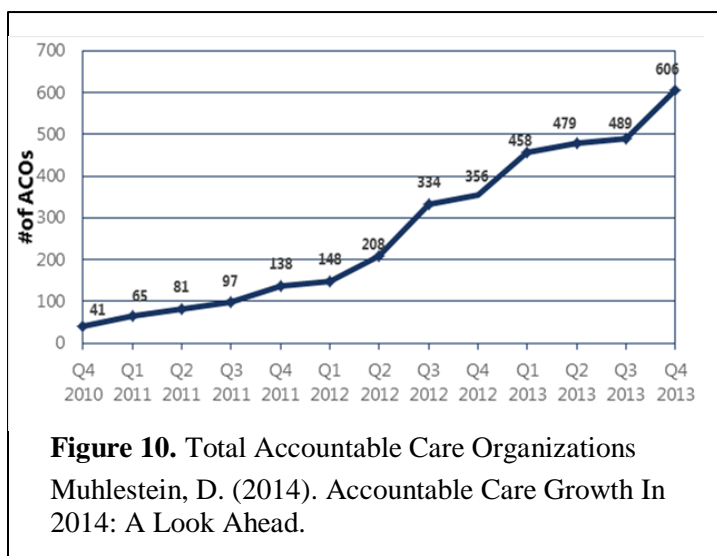
Indeed, timely referral and access to palliative care and hospice has been shown to drastically reduce health expenditures (Morrison 2008, Morrison 2011, Meier 2011). A recent report by the Institute of Medicine projected that fully integrating palliative care teams into the nation's hospitals would lead to over \$6 billion in savings annually (Yong 2010). Some of these savings can be traced back to addressing pain and symptoms upfront and thus reducing later hospital complications, as well as helping patients avoid hospitalization altogether (Meier 2011). Even at its current state, the palliative care programs that are established in around 60 percent of U.S. hospitals save an estimated \$1.2 billion per year in health expenditures; this figure would

grow to \$4 billion per year if palliative care were integrated into all appropriate discharges at 90 percent of U.S. hospitals (Morrison 2008). Hospice likewise has been found to reduce costs per beneficiary by around \$2,300 on average, amounting to total savings of over \$3.5 billion per year. Maximum savings are reached with approximately 7 weeks of hospice use, saving \$7,000 in Medicare spending per cancer patient and \$3,500 for others (Taylor 2007). The 7-week duration, however, is a far cry from the current median length of around 18 to 19 days, with 16.3 percent of total cancer patients in hospice enrolling within the last three days of life (NHPCO 2012, O'Connor 2014).

The evidently ineffective use of medical resources reflects poor coordination and fragmentation of care at the end of life, which the Institute of Medicine has identified as a key problem in both the delivery of patient-centered care and the payment policies in our health care system (IOM 2014). Further factors driving current levels of health care spending include our fee-for-service payment system, fragmentation in care delivery, aging population and rising rates of chronic disease, and lack of transparency on quality and cost, among others, according to the Bipartisan Policy Center (BPC 2012). One major way the ACA addresses this is through the formation of accountable care organizations (ACOs), or groups of health care providers who come together to offer coordinated care for patients in that ACO. The goals of ACOs are outlined in three core principles: First, ACOs are based in primary care but collectively are responsible for the full continuum and coordination of patient care. Second, payments are linked to quality; while ACOs do not completely do away with the traditional fee-for-service payment system, quality-based incentives streamline the system toward providing more efficient and coordinated care in hopes of reversing the costly and lower-quality results of a fragmented pay-for-volume system. Finally, ACOs are encouraged to develop more reliable performance measurements

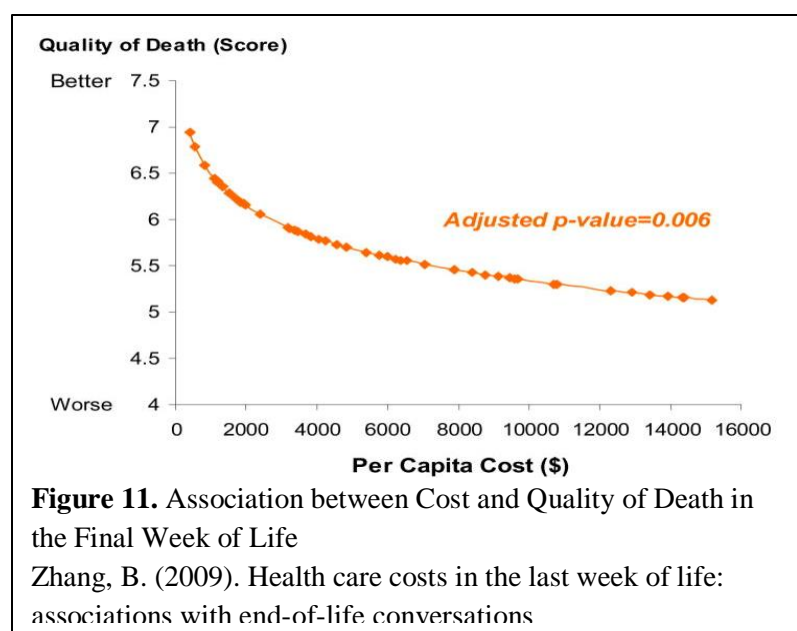
linking savings to improvements in care. These three guiding principles — coordination of care, reduced expenditures, and performance measurement — are captured in the ACA’s Pioneer ACO Program and the Medicare Shared Savings Program (MSSP), under which ACOs are formed. In the first year of the program, Pioneer ACOs saved Medicare an estimated \$147 million. These preliminary savings are modest — merely \$20 saved per beneficiary per month — though reported quality measures showed improvement where comparable data was available, using metrics across four domains: patient experience, care coordination, patient safety, and preventative health and at-risk populations (L&M 2013, Petersen 2014). Combined savings from both the Medicare ACOs and Pioneer ACOs exceed \$380 million, while the ACA as a whole is projected to save \$5.7 billion in hospital expenditures this year (U.S. Dept. Health and Human Services 2014; Pear 2014).

ACOs play a major role in outlining the future state of American health care. Already, 5.3 million people across the country are covered by more than 600 ACOs — the vast majority of which are physician group ACOs and hospital system ACOs (Muhlestein 2014). (Figure 10)



Besides facilitating the “volume to value” transition in health care payment, ACOs offer the potential for more coordinated and efficient care, which is of particular importance to end-of-life health care outcomes and spendings. Indeed, Pioneer and MSSP ACOs are currently serving mostly the elderly, with patients over the age of 65 comprising 85 percent of patients covered per

ACO (CMS Fast Facts 2014). For many of these patients, consolidation of care under an ACO may provide a “one-stop shop” for more integrated care, continuous patient-doctor conversations and better compliance with end-of-life wishes. A key strategy identified by the National Hospice and Palliative Care Organization involves ACOs contracting with post-acute care facilities to provide better chronic disease management, interventional palliation, and hospice care (NHPCO 2011). These partnerships aim not only to drive down health care expenditures but also to provide higher quality care and better adherence to the quality measures outlined by the ACA.



A study in 2009 reported that cancer patients who had end-of-life conversations with their doctors experienced better quality of death as well as fewer medical interventions and lower health-related expenditures within the last week of life (Zhang 2009).

(Figure 11) These findings, taken

together with the preliminary data gathered on existing ACOs, highlight the quality and cost benefits of integrating care under ACOs and the potential for greater future incorporation of palliative and end-of-life care within the conventional medical framework.

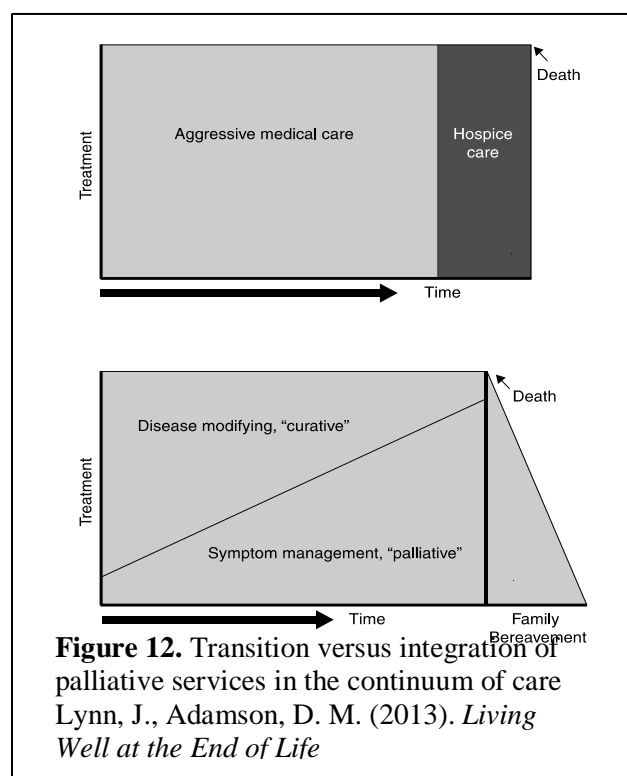
## CONCLUSIONS & FUTURE DIRECTIONS

The last several decades have seen tremendous growth in the technologies and corresponding expanding limits of medicine. With it, however, has also come a change in our attitudes toward life and death — a change that is largely reflected in increasing life expectancies, medical interventions at the end of life, and the propensity for deaths taking place in hospitals, even as patients indicate they wish to die in their homes. Within this context, the hospice movement, in the form of the Medicare Hospice Benefit, recast the spotlight onto quality of care, challenging patients and clinicians alike to reevaluate goals of care. As the stigma surrounding end-of-life care and the dying process has lightened over the years, policymakers have likewise begun to push for legislation emphasizing the importance of advance directives and advance care planning conversations among patients and their caregivers and doctors.

While the Patient Protection and Affordable Care Act of 2010 is perhaps the largest effort toward health care reform in the U.S. to date, it is notably devoid of discussions regarding end-of-life care. A predecessor to the ACA known as the America's Affordable Health Choices Act of 2009 failed to pass through the House of Representatives due to major controversies, one of which was raised as a result of Section 1233, which would have authorized Medicare reimbursement for physicians providing voluntary counseling regarding advance directives and end-of-life planning. The provision was slammed by former Republican Governor of Alaska Sarah Palin for promoting “death panels,” a sound-bite that quickly instigated widespread debate across the country. Despite the fact that the myth was extensively debunked by physicians, academics, and legislators, the equivalent provision was removed from the Senate bill and was not included in the Patient Protection and Affordable Care Act. Despite the political firestorm, however, advance planning and utilization of hospice and palliative care services have steadily

risen over the past decade (Silveira 2014; Goodman 2011). Hospice and palliative medicine gained recognition as a formal subspecialty of medicine in the U.S. in 2006, spurring an increase in the number of hospitals with palliative care programs and better understanding of the medical legitimacy of the non-curative goals of palliative care and hospice among both patients and medical professionals. Between 2000 and 2011, the number of hospitals with palliative care programs increased by 138 percent — though despite such progress, the Center to Advance Palliative Care notes that greater efforts are required in improving the availability of palliative care, as even following the growth, only 63 percent of hospitals in the U.S. offer palliative care programs (CAPC 2011).

While the ACA is notoriously nebulous in its language, certain provisions hold great potential to improve quality of American health care. The Medicare Care Choices Model (MCCM), for example, is a trial program established under the CMS Innovation Center. The



MCCM, initiated in 30 hospices across the country, allows Medicare beneficiaries to receive palliative care from approved hospice providers while simultaneously receiving curative-intent treatment, challenging the Medicare Hospice Benefit's current prerequisite that patients must forgo curative care in order to qualify for hospice enrollment. As CMS plans to begin delivering MCCM services starting around early 2015, preliminary data will hopefully reveal the

value of better integration of palliative care across the spectrum of curative and end-of-life care (Figure 12). Another notable product of the ACA is the establishment of accountable care organizations, which have already begun to take hold across the country, numbering over 600 with the rate of growth showing signs of picking up speed. A 2014 study funded by the National Institute of Aging showed that, when compared to patients under non-ACO providers, patients in ACOs report significantly improved timely access to care and information of their primary physicians about their specialty care. Among patients with high predicted Medicare spending and multiple chronic conditions, ratings of care were significantly higher among ACOs (McWilliams 2014). These findings, though preliminary, are encouraging indicators of improved communication and quality of care. Integration of care across specialties, including palliative care and hospice, further serve to help guide patients in their transition from the “sick role” to the “dying role” — a setting that more fully engenders appropriate discourses and quality measures for the terminally ill. Amidst the constant development of life-prolonging medications and technologies, aging and terminal illness are likewise increasingly pertinent in society and in health care. Both call for better end-of-life care and a health care system that can legitimize and cater toward the non-normative, non-curative-intent needs of terminally ill patients and the elderly. Furthermore, these trends emphasize an increasing need to recognize the natural courses of aging and illness. Disembodiment of these conditions — such as by framing the experience as a “war” against our bodies — only fails to help us manage and make sense of inevitable aging, illness, and mortality.

In reality, the dying role and sick role are merely terms to characterize the way our society polarizes these two approaches toward health care. Comfort- and curative-intent treatments are equally important means toward the end goal of quality patient care and are not

mutually exclusive, as some of our cultural attitudes may imply. While a large spectrum exists across the continuum of care, the goals of our health care system should aim to foster strong doctor-patient relationships that improve the quality and cost-efficiency of care as clinicians and patients alike traverse and make sense of the landscape of health and illness. The Affordable Care Act represents a major step in defining and supporting our goals of care by expanding coverage while promoting quality over volume of care to hopefully drive down costs of care. Nevertheless, further steps must be taken to expand quality and care coordination and advance care planning into “mainstream” health care even prior to hospice enrollment. As the formal and expert recommendations gathered by CMS indicate, this would involve accounting for social determinants of health as well as behavioral forces and improved quality management across the spectrum of care. Ultimately, many of the transitional challenges we face in end-of-life care are results of intersecting shortcomings of our health care system and unrealistic cultural beliefs about death and dying. As the ACA more fully unfolds in the coming years, implementation of more comprehensive quality measures may go a long way in legitimizing discourses on aging and advanced care as well as improving the use of appropriate palliative and hospice services.



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