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Transforming End-of-Life Care

By Jim Kessler, Susan Lexer, and David Kendall

The last year of a person's life is often physically painful, emotionally lonely, and shockingly expensive. Most Americans would prefer to die in the familiar surroundings of their home, surrounded by friends and family, rather than in a hospital or nursing home. The reality is that millions of Americans don't have their wishes honored. Instead, they receive costly and aggressive medical treatment at the end of their life that only marginally, at best, increases their life expectancy—often at the expense of their quality of life. But in some areas of the country, end of life is managed much more in accordance with patients' wishes through a coordinated system of patient-first advance directives and advanced illness care planning that appropriately directs medical personnel. The result is far less hospitalization, far fewer ineffective treatments, and as a by-product, far less expense. These areas can serve as a model for how to reform a piece of our health care system in a way that protects patients and significantly drives down costs for Medicare and the rest of health care.

THE PROBLEM

End-of-life care is often unwanted, ineffective and expensive

Health care at the end of life is broken. At a time when patients are trying to cope with the prospect of dying, the deeply ingrained habits of doctors and the procedures at hospitals stand in the way of getting the kind of care they want and need. Patients often prefer less treatment and more comfort—both physical and spiritual comfort—but they don't have a straightforward way to get all those involved—from doctors to family members—to heed their wishes.

Patients' wishes are too often unknown or unheeded.

In a survey of 2,515 Medicare patients with a mean age of 76, 86% preferred to spend their last days at home as opposed to a hospital or nursing home. 77% did not want to be put on a ventilator even if it would add one month to their life. 72% preferred comfort-promoting drugs, even if they might be life shortening. 84% did not want to take potentially life-prolonging drugs that made them feel worse all of the time.¹

But what elderly patients want and what they get are entirely different. For example, although 75% of Americans feel advance directives are a good idea, only 40% of Medicare patients say they have one. Even if they do have an advance directive, it is no guarantee whatsoever that medical personnel will be aware of their wishes or follow them. Many patients sign documents that don't offer clear instructions. Family members may have conflicting feelings about the care they wish to see a patient receive. Some physicians simply do not comply with instructions.² Often end-of-life instructions never make it to medical personnel including paramedics.

For elderly patients, their end-of-life wishes regarding care are often unknown or ignored. "We did not find a relationship between individual patient preferences and local practice patterns, since ... preferences are seldom correctly ascertained, let alone heeded," according to a study on end-of-life care in the journal *Health Care*.³ Many patients are naturally not assertive in health care settings, so the training of medical personnel to treat disease aggressively can overwhelm patients' true wishes. In addition, patients' wishes can change over the course of treatment.

Patients too often receive more care instead of better care.

More care, as it turns out, is not always better care. "We basically see no relationship between spending more and living longer," said Dr. John Wennberg of the Dartmouth Atlas project and co-author of a report that tracks health care expenditures and outcomes between regions.⁴

The current fee-for-service payment system and the culture of medicine favor aggressive care even when it is unwanted and impractical.⁵ It rewards more treatments, not necessarily better treatments.

"One of the things that frustrate us all is to see care being provided in an absolutely futile situation. Doctors and hospitals are not accountable but are also being rewarded for [futile] care," according to John Santa, former medical director for the Center for Evidence-Based Policy in Oregon.⁶

End-of-life expenses are shockingly high and widely variable.

27% of Medicare's budget covers the last year of a person's life.⁷ Over the next 10 years, Medicare will spend more than \$1.7 trillion dollars simply covering the medical costs of a person's last year.⁸ But there is wide cost variation from place to place. Some of the variation is due to regional differences in the cost of living. (Most things in Minot are less expensive than the same things in Manhattan.) But certain differences cannot be explained simply by the cost of goods and services.

A dying person in Miami saw doctors, mostly specialists, 46 times in the last six months of life. More than one-fourth died in an ICU. And the medical cost was just over \$23,000 per person. In Portland, Oregon, dying persons saw a doctor 18 times, mostly a primary care physician. They spent on average just one day in ICU and the tab was about \$14,000.⁹ Half as many per capita Medicare deaths occurred in Minneapolis hospitals than in Chicago or Los Angeles hospitals. The affluent retirement community of Sun City, Arizona had one-fourth the amount of ICU visits in the last six months of life compared to the retirement communities of Sun City, Florida and Sun City, California.¹⁰ End-of-life costs in Green Bay, Wisconsin were 70% the national average.¹¹

THE SOLUTION

Honoring Patients' Wishes with Advance Directives that Matter

Our solution calls for the following three simple steps:

- 1. Patient Wishes** – Offer and encourage every Medicare beneficiary (and working adults, too) to fill in and file a simple and comprehensive advance directive form.
- 2. Doctors Orders** – Require and train medical personnel to honor patients' end-of-life wishes including placing the directive on patients' electronic medical records.
- 3. Specialized Advanced Illness Care** – Provide advanced illness care through a team trained for end-of-life care that consists of a physician, nurse, social worker, and spiritual counselor.

All Medicare patients should have ready access from a variety of sources to a simple advance directive form along with a method of filing that form with providers, Medicare, and family. In addition, doctors and other health professionals should initiate a series of conversations with their patients and family members about hospice care and palliative care for advanced illness. Today, those conversations occur only half the time, and even less often for minorities and the poor

according to a study of patients with terminal lung cancer.¹² And when they do occur, they often come shortly before death.

Several bills in Congress would help honor patients' wishes. The Advance Planning and Compassionate Care Act of 2009 (S. 1150) introduced by Sens. Rockefeller (D-WV) and Collins (R-ME) and the Life Sustaining Treatment Preferences Act of 2009 (H.R. 1898) introduced by Reps. Blumenauer (D-OR) and Boustany (R-LA) would expand access to advance directive forms through online services and legal clinics, promote the use of physician orders based on advance directives, and encourage medical consultations about end-of-life care. They would also make advance directives portable across state lines, increase the number of physicians and other health professionals trained in advance illness care and increase research in end-of-life care.

Sen. Mark Warner (D-Virginia) and Rep. Tammy Baldwin (D-Wisc.) have introduced the Senior Navigation and Planning Act of 2009 (S. 1263/H.R. 3172) to promote advance care planning in non-crisis situations. The legislation would help seniors, their families, and caregivers navigate through the maze of health care choices by providing Medicare coverage for care specifically designed for patients with advanced illness.

Third Way's recommendations would take advantage of Medicare's market power to lead a transformation of end-of-life care. The same efforts could also apply to the non-elderly for the times when tragically, they need end-of-life care, too. For example, the Rockefeller and Blumenauer bills would increase options for palliative care for children with terminal diagnoses.

Taken in total, these steps could result in considerable savings. Third Way estimates \$40 billion in savings to Medicare over ten years. Here is what would happen under a transformation of end-of-life care.

Patients would have more effective ways to express their wishes.

Federal action would cause more communities to do what communities like Sun City, Green Bay and Oregon are already doing to promote the use of advance directives. Those areas of the country have ample hospital beds, specialists, and medical technology, but lower costs. One key difference between these regions and most others is that each has actively encouraged senior citizens to have advance directives and each put a premium on health care providers following those directives, rather than ignoring them.

Sun City, Green Bay, and Oregon have developed a simple, patient-first means to ensure that individual preferences for end-of-life care are documented and made known to medical personnel.

Sun Health, a private non-profit health care system in Sun City began the citywide “Vial of Life” program in the 1990s. It provides a free, specially labeled 6-inch medicine bottle for medical documents as well as identification stickers for the front door and refrigerator. Each vial is stored in an individual’s refrigerator and includes a form listing a patient’s vital statistics, medical history, medications, hospital preference, doctor’s orders, insurance information, allergies, and emergency contact information. It also includes an optional do-not-resuscitate (DNR) form and can hold a Living Will or other important health care documents. The vials allow emergency responders to get critical information quickly at a time when patients may be unable to speak for themselves.

Green Bay and La Crosse encourage patients to sign advance directives and make sure that they are part of their electronic medical records. “At the end of life, what most people want is for their wishes to be respected,” not to undergo an aggressive battery of tests and treatments, said Jeffrey Thompson, chief executive of the Gundersen Lutheran Health System in La Crosse, Wisconsin.¹³

Doctors and medical personnel would have new tools, professional ethics, and incentives for honoring patients’ wishes.

In Sun City, Green Bay, and Oregon, advance care planning tools are developed and presented in a way that respects individual patient preferences and autonomy. In turn, medical personnel recognize and respect the explicit treatment intentions specified in each document that results in the patient receiving the appropriate level of medical care in accordance with their preferences.

In 1995, Oregon developed the “Physician Order for Life Sustaining Treatments” (POLST) program in an effort to improve end-of-life care by converting patients’ medical treatment preferences into medical orders that are easily transferable throughout the health care system. The program enables seriously ill patients to identify their treatment preferences using a clear, standardized, brightly colored form. The POLST form allows patients to communicate their preferences regarding intensity of medical intervention, transfers to the hospital, use of antibiotics, artificially administered nutrition (feeding tube), and resuscitation. Emergency medical personnel know to look for a POLST form on a patient’s refrigerator and to make sure it accompanies a patient if they are taken to a hospital or other medical facility. A bill moving through the Oregon state legislature would create a voluntary, state-wide register of POLST forms so they will be available 24 x 7 to medical personnel.¹⁴

As a result those efforts, the failure to follow an advance directive is now considered a medical error in Oregon. In Arizona, health care records, including the advance directive, are put on the computer file of each elderly patient. In both places, medical personnel and patients have a clear understanding of what

the directive means in terms of intervention. In La Crosse, one of the leading health care providers actively encourages participation.

The Warner-Baldwin bill would give doctors an additional reason to honor patients' wishes: they wouldn't get paid for services that patients had explicitly refused. The bill would establish clear standards for the documentation of a patient's wishes that doctors and hospitals would use to be paid. Doctors and hospitals would also need a clear legal standard that protects them from legal liability when they follow a patient's request not to be resuscitated. Once the regulatory and legal standards are in place, then Medicare should not pay providers for services that go against a patient's wishes.

Patient would have access to specialized advanced illness care.

Care at the end of life or for patients with advanced illnesses is a deeply personal matter for individuals and their families, and can have profound cultural and religious implications. It needs to address these spiritual needs along with physical needs. It starts with eliciting the values and preferences of patients about what kind of health care they want. It can be palliative care, which focuses on relieving the suffering from an advanced illness, or hospice care, which is specifically designed for patients who are dying. Discussions about the patient's care should also involve family members, their concerns and the support they need.

From there, patients can draft an advance directive in accordance with their wishes, seek services such as pain control, and receive personal and spiritual support. Today, Medicare requires patients to choose between curative care through traditional providers and palliative through hospice. Instead, good palliative care should be available before a patient is ready to give up on curing a disease.

Two of the nation's leaders in advanced illness care are United Healthcare's Evercare program and Kaiser Permanente. Both have proven that the team approach increases patients' sense of well-being, and as a by-product, it significantly reduces costs in a variety of health care settings and organizations.

Evercare makes extensive use of nurse practitioners (nurses with advanced education and training) to work closely with patients and their primary care physicians in order to address physical, psychological and spiritual needs. An Evercare nurse practitioner, Renee Roberts describes herself as a clinician, counselor, coach, communicator, manager, and collaborator.¹⁵ Performing such varied roles with patients in nursing homes, Evercare's nurse practitioners have cut hospitalizations in half.¹⁶

Kaiser has tested this specialized end-of-life care in hospitals, physician offices, and patient's homes. In the home-based programs, for instance, savings were \$7,500 for every patient enrolled.¹⁷

According to Kaiser's Aging Network's Medical Director, Richard Della Penna, MD: "Palliative care teams have the time to meet with patients and families to discover their view and values and support them in their decisions, plans, and hopes."¹⁸

The Warner-Baldwin bill would authorize a new advanced illness care management benefit based these kinds of programs. It would be administered by hospice providers for any patient with a life expectancy of 18 months or less. It would end the requirement that patients give up traditional, curative care in order to receive advanced illness care.

This bill also requires physicians and hospitals to provide patients with information on living wills and other planning tools. It encourages hospitals to provide more comprehensive discharge planning. Finally, it would expand access to advance illness care by providing hospitals, nursing homes, and physicians with incentives to receive accreditation and certification in hospice and palliative care.

The Rockefeller and Blumenauer bills also promote palliative care teams in hospitals. Additionally, they include demonstration projects to test new ways to pay for palliative care across different places where patients with advance illness receive care.

Health care costs would fall as a by-product of better end-of-life care.

By reducing ineffective and unwanted care, living wills, advance directives, and increased use of hospice care can significantly reduce the amount of money Medicare spends during a beneficiary's last year of life while giving the elderly the care they desire. Due to cost sharing requirements associated with Medicare, the patient, his or her family, and supplementary insurance providers could also benefit from the potential cost savings.

"If medicine were practiced in the rest of the country as it is in Sun City, you could at least extend the Medicare Trust Fund solvency for another 10 years," said economist Jonathan Skinner, co-author of a report on end-of-life care.¹⁹

As studies have shown, there is enormous variation in the cost of end-of-life care across the country. Sun City, Arizona and the state of Oregon have some the lowest rates of health care spending at the end of life—roughly 60% of the national average. On average, end-of-life patients in these areas have fewer visits to the hospital, shorter hospital stays, and fewer visits to the doctor than nearly anywhere else in the country.²⁰

Based on the savings from the Evercare and Kaiser studies and the additional studies below, Third Way has estimated that Medicare could save roughly \$40 billion over ten years by making end-of-life care patient-centered:

- A 2009 study published in the *Archives of Internal Medicine* found that patients with advanced cancer who reported having end of life conversations with their physicians had significantly lower health care costs in the last week of life. The mean cost of care was \$1,875 for patients who reported having end-of-life discussions compared with \$2,917 for patients who did not, a cost difference of \$1,041 (35.7%) in their final week of life. In addition, higher costs were associated with worse quality of death.²¹
- A 1996 study published in the *Journal of the American Medical Association* examined existing data on patients' end-of-life care preferences, including the use of hospice and advance directives. It determined that these strategies combined could potentially save between 25% and 40% of health care costs during the last month of life.²²
- A 1994 study in the *Archives of Internal Medicine* found that Medicare beneficiaries with living wills or similar documents spent a third as much on their final hospital stay than those without such documents, dropping the costs from \$95,305 to \$30,478.²³

■ CRITIQUES & RESPONSES

How is this different from physician-assisted dying?

This is completely different. This is about the decisions that millions of families face year after year—about whether the final weeks of life will be in a hospital or a home, in surgery or in comfort, with the most aggressive treatment or palliative care, on a feeding tube or on one's own. Having a clearly written advance directive just makes sure that people's wishes are known and followed.

Suppose I change my mind?

The advance directive is simple and changing it is simple as well. It's your record to do with what you want. It is used only when you cannot speak for yourself and you are going to die without artificial life support.

What if someone doesn't fill in his or her form?

No one would be penalized for not filling in an advance directive form. And the default would be the same aggressive medical treatment that patients get now.

This seems coercive—forcing Medicare patients to confront a very difficult decision.

This is the opposite of coercion. We're giving every Medicare patient the opportunity for choice and to exert control. They do not have to fill anything out that they don't want to.

Does this comport with biblical teachings?

This is not physician-assisted dying. This is about whether elderly people in the final weeks and months of their lives want to have aggressive surgery and procedures that are designed to add a few weeks to their lives or whether they want care that focuses on comfort. In fact, we want to disseminate information on this program through religious institutions, because no one knows more about dealing with the final days of life than religious leaders. For example, a recent New York Times article highlighted how the Sisters of St. Joseph convent in Pittsfield, NY helps its members die gracefully without excessive treatment.²⁴

I've seen studies that say that advance directives don't save money. Is that true?

Advance directives don't save money unless health care providers follow patient wishes. They can help save huge sums of money when those wishes are followed as part of comprehensive end-of-life care. And that's what this initiative does.

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■ ENDNOTES

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