



We Must – and We Can – Do Better

By IRA BYOCK, MD

Despite more than three decades of earnest efforts to improve end-of-life care, a crisis persists in the way we die.¹ It is a man-made crisis, although no one is to blame. Perhaps, in a sense, we are all at fault for wanting to bring every ounce of science and technology and every dime to bear to protect and preserve life.

Surely we can be forgiven for that. Still, we must craft a better way forward. We live in unprecedented times and face social and ethical predicaments that no other nation or society has encountered.

- For the first time in the history of humankind, there soon will be more people older than 60 on our planet than there are people who are 20 or younger.

- Thanks to advances in medicine, millions of people now survive many cancers, heart damage, kidney failure and other conditions that would have rapidly ended their lives even a few decades ago.

- People are now sicker before they die than at any time in human history.

We are fortunate to have ever-more effective treatments available for late-stage diseases — from biological cancer agents and stem cell therapies to left-ventricular assistance devices to kidney, heart and liver transplants. Yet these life-prolonging therapies often make it difficult to know when it is time to let life go.

A better way forward is possible. In effect, we have been approaching serious illness and dying from the wrong direction. As a result, all of our good intentions and substantial investments of time, energy and money inadvertently have perpetuated patterns of excessive treatments and inattention to people's personal needs.

SHIFTING THE FOCUS TO PERSONS

Contemporary America's health care system is actually a disease detection and treatment system. We are rightly thankful for the prowess that science has given us to diagnose and treat disease. But while diagnoses and treatments are medical, illness and dying are personal — profoundly so. In seeing only the medical aspects of illness, we keep missing the obvious and bring the wrong tools to the job of caring well for dying people. Filtered through billing codes and criteria for “medically necessary” services, people's personal needs remain largely unseen. The inattention is not malicious, but it is

negligent.

Better care is not esoteric. People who are facing the end of life want competent treatment for their symptoms, and they want

to be assured that they will not suffer horribly as they die. They want to know that their families will be supported in care giving and in grieving. Beyond these basics, many patients have asked me, “How do I do this? I've never died before.” They want guidance in the work of completing their affairs and relationships and in closing their lives gracefully.

Since the mid-20th century, we have been training doctors to be technicians more than clinicians. While technical skills and tools are valuable, they are insufficient.

Despite modest improvements in the past decade, American medical education is failing its trainees, who go on to fail their patients. It is not the fault of individual physicians. Still, it is fair to say that when it comes to end-of-life care, society is not being well served by the doctors it educates, licenses, certifies and compensates.

Doctoring that responds to the personal experience of illness and dying can be taught, and the results are satis-

fyng for patients and physicians alike. However, adequate training requires more than a day or two of curriculum time.

SYSTEM-BASED SUFFERING

The business of American medicine contributes to making dying harder than it has to be. An extensive exposé in *Time* magazine by journalist Steven Brill in March 2013² and a subsequent *New York Times* series reveal how a medical-insurance-industrial complex inflates prices, CEO compensation and shareholder profits.^{3, 4, 5} The “more is better” business model of American medicine sees the detection and treatment of diseases as income opportunities, but it views caring for people with serious illness as a chore and added expense.

It’s an expense that insurance and health care

systems often shift to sick people and their families through co-pays, uncovered prescriptions, deductibles, lifetime caps and out-of-pocket costs. Even reasonably well-to-do individuals and couples routinely are impoverished during a lengthy illness.

The resulting financial and social hardships have warped the ethical landscape of caring. As a student and young physician, I assumed that dignity was a settled matter of clinical ethics. In 1948, the United Nations’ “Universal Declaration of Human Rights” had recognized the inherent dignity of all members of the human family. Yet I soon learned that people in hospitals and long-term care facilities can be made to feel undignified when there is no one to relieve their pain, or when they need help in getting to the bathroom and nurses or aides are unavailable to answer their call.

THE SPIRITUAL CORE OF HUMAN EXPERIENCE

Excerpt from *The Best Care Possible: A Physician’s Quest to Transform Care Through the End of Life*, by Ira Byock, MD

A heightened awareness of the essential mystery of life and the potential to evoke terror and awe affects anyone who ventures close to a person’s dying. Confronted with the mystery of life — and death — we reflexively try to make some meaning of our experience in the world, strengthen our relationships with others, and feel part of something larger and more enduring than ourselves.

Throughout time and across cultures, people have conveyed wisdom for dealing with life’s mysteries through religions. Anthropologists and archaeologists have found evidence of spiritual practices throughout human history. Religious teachings, customs, rituals, traditions, stories, and songs have guided individuals and families through births and deaths, celebrations and grief. Not surprisingly, people who have a deep religious faith often feel it is a source of strength and comfort in dealing with illness, caregiving, death, and grief.

Spirituality is rightly considered the province of religion, but it is not an exclusive province. Accompanying people who

are dying has taught me that human life is inherently spiritual, whether or not a person practices a religion.

One afternoon in clinic, I asked Mr. Grady, a gruff, wizened farmer from Thetford, Vermont, if he considered himself a spiritual person. It is a question I ask every patient, unless the person has already volunteered information about his or her beliefs. I ask, because I can’t count the number of times I would have surmised wrongly.

“Nah, not me,” Mr. Grady said with a wry, tight smile. Congestive heart failure and lung disease gave him the habit of delivering short, considered bursts of words, all spoken in a thick New England brogue.

I probed a bit. “Do you have a sense of where we go after we leave this life?”

“Yup,” he replied with a chuckle, his smile giving way to a broad, toothless grin. “The worms go in; the worms go out,” he replied, his hand and wrist mimicking an undulate in motion.

I was curious about where he was planning to be buried. “Where will the worms go in and out of your bones, Mr. Grady?”

“Oh, we have a family cemetery on a hill in Thetford,” his tone now earnest

between pauses to breathe. “We Gradys have been buried there since the early 1800s.” Another breath. “I suspect my grandchildren and their grandchildren will be there, too.”

Mr. Grady didn’t pray, attend church, or believe in God. However, his strongly felt connection to the land and his family, including generations of ancestors that preceded him and generations that would follow, seemed authentically spiritual to me.

Our team members — and increasingly, clinicians in our field — sometimes use poetry to explore spiritual aspects of people’s experience.

Alice Fehling was a forty-seven-year old woman with advanced intraperitoneal cancer and ascites who was admitted to the hospital when her leg suddenly turned cold and blue. After the successful removal of an arterial clot restored circulation to the limb, she developed kidney failure. During rounds one Sunday morning, I visited Alice in her hospital room. Following the requisite pain and bowel update, we indulged in musings about illness, healing, God, and love. The conversation began when I asked about the collection of Rumi’s poems on her bedside table. We read a few and then I



WRONG WORDS, WRONG ACTIONS

Because a social and cultural dystopia clouds individual decision-making and the national conversation about how we die, the public is disheartened and angry. People have seen loved ones suffer or languish in ICUs, hospitals and nursing homes, and many fear the prospect of caring for aging parents in the years ahead. Their trust in the medical profession is low. In this muddled morass, the so-called “Right to Die” or “Death with Dignity” movement has emerged as the most prominent outlet for people’s fear and frustration.

“Right to Die” is an effective slogan, but little more. No civil right to suicide exists in any social compact. Euphemisms such as “aid in dying,” “self-deliverance” or “hastenings” disguise a primitive response to basic human needs. The phrase “Death with Dignity” sends a message to

elderly or ill people that in order to remain dignified, they need to die before becoming senile or physically dependent.

One need not accuse the assisted suicide movement of being maleficent to acknowledge that the results are pernicious.

Sanctioning suicide or euthanasia is not the solution to the crisis that surrounds how people die. Oregon-style “Death with Dignity” Acts do not make physicians better at treating pain, or communicating well, or skillfully guiding people through the inevitable challenges of being mortal. Such laws do not improve staffing in nursing homes or fix the injustice of requiring sick people to give up treatment for disease in order to receive hospice care for their comfort and well-being and their families’ support. While cloaked in the progressive language of rights, in the midst

shared a favorite poem and asked her to guess who wrote it.

*You do not need to leave your room,
Remain sitting at your table and listen.
Do not even listen, simply wait.
Do not even wait, be quiet, still and
solitary.
The world will freely offer itself to you
to be unmasked.
It has no choice.
It will roll in ecstasy at your feet.*

“That’s wonderful, but I have no idea who the poet is.” Alice said.

“Franz Kafka,” I replied.

Alice was surprised that Kafka, the quintessential existentialist whose writing typically portrayed the universe as cold and impersonal, leaving each individual exposed to circumstance and happenstance, would offer a vision of an ecstatic world. This led Alice and me to talk about chaos theory, fractals, and patterns within randomness. She spoke about healing and well-being in the face of loss and her sense of God within us all and all that is. She knew she was dying and hated to leave her husband with whom she felt ever more deeply in love. Alice said that except for her physical

ailments, she had felt “well” and alive in these last few months.

The spiritual impact of death’s approach is often felt by those who know and care for a person who is ill. Birth, illness, and death, even with the financial strain, time pressures, and turmoil in health care, imbue clinical care with a spiritual dimension.

Doctors and nurses only rarely talk to one another about these things. However, over the years many colleagues have spoken to me about accompanying patients in their final days, hours, and moments before death. Again and again, the words, “privilege” and “sacred,” are part of their descriptions. “There was something sacred about being there when Mrs. Jones passed.” Or, “It was a sacred moment for the family,” adding, “for me, too.” Along with, “It was a privilege to help care for Mrs. Jones. I feel fortunate to have been there as she died.” Or simply, “What a privilege!”

My unscientific sample suggests that the experience of sacredness and privilege in the presence of these events is shared by people of all religions, politics, and temperaments. I have exchanged nods of silent recognition of the indefatigable quality of people’s deaths with

unsentimental surgeons and tightly wrapped intensivists. It is not just the end of life, but somehow a culmination of human experience. To those who have had the experience, no explanation is necessary; to those who have not, no explanation will be sufficient.

None of this suggests that modern clinicians harbor a religious agenda. My sense is that “sacred” is merely the word that most closely fits what many of us experience. “Sacred” is experienced—physically and emotionally—as complete rightness in the moment. The sacred is not reasoned or abstracted, but felt. It is phenomenological or anthropological, rather than theological or medical. Within the sacred, the mystery of life is miraculous. There is no terror, only awe. All paradox and conflict are resolved, or, more precisely, dissolve. ...

This is not intoxication in any sense. In fact, it is a deep awareness of the true nature of reality, a sense of being fully, firmly grounded.

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of serious deficiencies in medical and long-term care, the legalizing of assisted suicide represents acquiescence to failed social policies, clinical practices and woeful deficiencies in personal care and social support.

We can do better than that. A wealth of studies demonstrates that much better end-of-life care is achievable and affordable. In the hands of skilled, highly developed teams, people's comfort and sense of well-being can often be preserved, even in dire circumstances.

SCALING UP MODELS THAT WORK

The deeper solution to this crisis requires seeding the collective imagination of the public with reliable, humane and dignified alternatives to suicide and euthanasia. The public is hungry for hopeful narratives and images of real people in the most difficult situations being cared for in skilled, respectful and loving ways. The evidence that such caring can happen is plentiful, but so far it has failed to capture the public attention.

Enlightened assisted living and continuing care programs, such as PACE (Program of All-

Inclusive Care of the Elderly)^{6,7,8} have shown that by integrating health care, social services, nutrition and transportation, it is possible to affordably meet the needs of frail elders who would otherwise be relegated to woefully understaffed nursing homes. Eden Alternative, Greenhouse, Pioneer Network and similar programs have reinvented long-term care, infusing community values, pets, plants, children, laughter and joy into the lives of institutionalized elders. Innovative clinical services, such as "open access" hospice and palliative care, enable people to receive comprehensive attention to their comfort and quality of life, while also receiving state-of-the-art disease treatments. Evidence-based counseling modalities are available to enhance an ill person's sense of dignity, completion and well-being.

Programs that are pushing the envelope in the most creative and heartening of ways exist within many of our own institutions and communities, but at present they are reaching a small fraction of those who would benefit. The swelling numbers of frail elders and chronically ill people in our communities make it clear that the time for small-scale change has passed. The work before us entails swiftly bringing to scale best practices and innovative programmatic models and proudly telling the stories of our programs, teams and the people we serve.

Enlightened and reliably effective approaches to care must be publicized, opened to journalistic inspection and debated, thereby becoming part of the national psyche, expanding our collective imagination and raising expectations of what is achievable. A noteworthy example is a *New Yorker* magazine article about Beatitudes, a dementia care facility in Arizona that is at once remarkable and intuitive.⁹ The stories of the people who live or work at Beatitudes allow readers not merely to understand, but to imagine and feel how good care and a frail person's quality of life can be in circumstances that many now believe are worse than death.

This is a propitious time to foster radically positive change. Value-based payment reforms in which providers of health care services share financial risk with payers are transforming the business model of health care from volume of services — "more is better" — to measured quality of services — "better is better."^{10,11}

This change is particularly hopeful for improving care for people with advanced illness because characteristics of patient-centeredness are now embedded within the definitions of quality¹² and

RESOURCES

Corrections for our cultural tunnel vision about illness and dying are plentiful, if we pay close attention. Stories of people's lived experience with dying reveal that many can achieve a sense of well-being during the last months, weeks and days of life. Within the literature of the field of hospice and palliative care, such stories are familiar, but only a few publications and media portrayals have entered the mainstream. Worthy examples of memoirs and biographies include:

Refuge: An Unnatural History of Family and Place, by Terry Tempest Williams

Tuesdays with Morrie: An Old Man, a Young Man, and Life's Greatest Lesson, by Mitch Albom

Learning to Fall: The Blessings of an Imperfect Life, by Philip Simmons

About Alice, by Calvin Trillin

Too Soon to Say Goodbye, by Art Buchwald

The Last Lecture, by Randy Pausch with Jeffrey Zaslow

The End of Your Life Book Club, by Will Schwalbe

"The Long Goodbye," columnist Joe Klein's account of his father's illness and dying, published in the June 11, 2012, edition of *Time* magazine

"StoryCorps," the independent national oral history project, <http://storycorps.org/>



reported measures of quality.^{13,14}

Furthermore, research clearly demonstrates that comprehensive patient-centered and family-centered models of care that involve shared decision-making, coordination and crisis prevention and crisis management plans are significantly less expensive than the current, solely disease-focused approach.^{15,16,17,18,19}

THE CULTURE IS WATCHING

As individual professionals and moral agents, this crisis is unfolding on our watch. Those of us in health care must accept nothing less than excellence. Pressures of finances, regulations and workload — and the seemingly ever-present tyranny of the urgent — can limit our sights to just getting by.

In the midst of these pressures, we can be generous and joyful in our clinical practices, as well as in our management of institutions, programs and personnel, while being uncompromising about quality. Each of our programs carries opportunities to innovate and elevate quality — first and foremost, for the sake of the people we serve, but also to enable colleagues to examine, learn from and, if deemed worthy, emulate our programmatic experiences.

We have a historic opportunity to contribute to a healthy maturation of Western culture by reasserting basic human values and the right of each person we serve to feel wanted, worthy and dignified through the very end of life. By melding clinical excellence and ethical clarity with authentic respect for each person's dignity, feelings, well-being, as well as their families' well-being, we can advance life-affirming values and vision within our society and culture.

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