

End-of-life Care in America: A Complex Systems Perspective on Biology, Beliefs and Behavior

The perplexing challenges associated with death and dying are neither new nor lacking for thoughtful research from a range of perspectives. Characterized by wide variation in the care of terminally ill patients, the U.S. health delivery system struggles with end-of-life care. Hardly an issue unique to the United States, meeting the needs of the terminally ill and their families represents a persistent challenge for western European health care systems as well. The enormity of the problem, and the complex web of interrelated issues associated with any attempt to address it, put us at risk of systemic paralysis unless we can change the tone of discussions from shrill to measured. Taking a first step in such a change in tone was the ambition behind an end-of-life symposium sponsored by Vizient in partnership with the Santa Fe Institute (SFI). The symposium was held on March 23, 2017 in Chicago and was attended by a national group of stakeholders broadly representing health systems from across the country as well as organizations outside of the health care industry.

The symposium adopted a blended format involving six sessions, each facilitated by a distinguished national thought leader with expertise in the biological sciences, critical care medicine, ethics or economics. Each session was carefully designed to include both a didactic presentation and a facilitated group discussion engaging all participants. The following summary of proceedings attempts to synthesize the scientific presentations and associated group discussions, distilling emerging themes whenever possible, and capturing the essence of the discussions in the hope that it advances not only the national dialogue around end-of-life care, but more importantly the grassroots efforts of local and regional stakeholders to better meet the needs of terminally ill patients and their families.

Timothy Buchman, PhD, MD, the founding director of the Emory Center for Critical Care, opened the symposium with a review of the epidemiology of aging and terminal illness. Even more striking than the doubling of the number of Americans over age 65 projected over the next 25 years is the growth in the population aged 80 years or older. Nearly 20 million baby boomers are expected to die in the next 15 years – an average of 1.3 million annually – most suffering from multiple chronic conditions that confound optimal balance between longevity and quality of life. Dr. Buchman identified four potential levers commonly used to change behavior: exhortation, regulation, simplification and incentives. Of the four, simplification is perhaps the most intriguing; by making the desired outcome the easiest to attain, we may outperform the less-effective behavior modification levers. This has implications for increasing patient engagement in new approaches to

end-of-life care. It suggests that solutions to the end-of-life dilemma are more likely to emerge from grassroots (bottom-up) initiatives than from top-down regulatory efforts. By making it easier for patients to make more informed choices about living longer and living well, simplification may represent the shortest route to progress.

E. Wesley Ely, MD, MPH, professor of medicine and critical care at Vanderbilt University and associate director of aging research for the VA TN Valley GRECC, opened his remarks centering on core ethical issues by reiterating a point raised by Dr. Buchman: the leading cause of death in intensive care units (ICUs) is the decision to stop support. Dr. Ely posited that medical professionals should reject life-prolonging procedures that are insufficiently beneficial or excessively burdensome in the eyes of the patient. He added that foregoing extraordinary or disproportionate means is neither suicide nor euthanasia but rather acceptance of the human condition in the face of death. Dr. Ely introduced the concept of the quality of a death, framing the struggle to balance longevity with dignity by suggesting that a more appropriate question than “What’s the matter with dad?” is “What matters to dad?” In what would emerge as one of the core themes of the symposium, the ensuing discussion considered the premise that a key determinant in what constitutes the “right” care at the end of life is what a well-informed patient genuinely wants. Perhaps the better measure of a quality death is viewed as matching a care plan to the patient’s informed preference. An 89-year-old who wants to see their great grandchild born may choose care that for another patient would be “disproportionate.” The right answer is not always less care, but the key to assessing the correct balance is a well-informed patient. In addition, Dr. Ely discussed the fact that there is a groundswell of activity around physician-assisted suicide and euthanasia globally, with a core ethical dialogue taking place with regard to the involvement of physicians in this process. He acknowledged that it is the patient’s right to reject life, and that at the same time there is a covenant between patients and physicians that importantly means the autonomy of both parties must be respected. The medical profession must uphold rights of conscientious objection for physicians who do not want to participate in the process of physician-assisted deaths. These discussions are important and timely because both the American Medical Association (AMA) and the World Medical Association (WMA) are discussing removing opposition to physician-assisted suicide and euthanasia. Such a decision would amount to a tidal shift in this ancient profession and affect end-of-life processes.

Jeffrey Thompson, MD, executive advisor and chief executive officer emeritus at Gundersen Health System, described a 25-year initiative that has resulted in more than 95 percent of the seniors in southwest Wisconsin having advanced care planning (end-of-life advance directives) during their last two years of life and a track record of local medical providers abiding by those advance directives more than 98 percent of the time. Dr. Thompson squarely confronted the conflict between effective advance directives and traditional revenue sources. More than 25 percent of Medicare spending occurs during the last year of a patient’s life and when advance directives result in lower end-of-life spending, providers see revenue fall under the traditional fee-for-

service payment system. The “why” in rationalizing end-of-life care must be mission-based, not economically motivated. Four lessons emerged from the experience in La Crosse, WI:

- Conversations and relationships with terminally ill patients are essential and the discussions must begin long before the ICU or even a hospitalization
- Each advance directive is highly personalized – predicting individual preferences is difficult and frequently wrong – and everything does not begin or end with the physician; success involves community resources and caregivers, including the clergy
- A common set of questions leading to a standardized advance directive document was critical to the program’s success, but the process for engaging each patient and their family was unique and intimate
- Accessibility of records is a necessary condition; the advent of electronic medical records will enable broader adoption

A theme first introduced earlier in the symposium was underscored by the Gundersen case study: changing the dynamics of end-of-life care is a local grassroots undertaking. Medical providers, faith-based organizations and community leaders need to play key roles in the transformation. Government policy – most notably Medicare payment regulations – can enable the process by eliminating barriers to progress, e.g. extending palliative care benefits earlier in a terminal episode while eliminating the arbitrary distinction between life-prolonging care and the hospice benefit, but changing policy will not ensure success...the heavy lifting occurs at the local level.

Geoffrey West, PhD, distinguished professor and past president of the Santa Fe Institute, led a session devoted to a quantitative theory of aging and mortality. Biological systems work and then wear out. What sounds at first like a simple proposition is in fact rooted in compelling mathematical relationships. Mammalian life expectancies fall very sharply along a predicted curve and demonstrate consistent economies of scale. Larger animals live longer because they enjoy scale economy with respect to the energy consumed by normal metabolism. But eventually, even larger organisms exhaust the capacity of their internal systems to absorb the rigors of metabolism. The result is a rather intractable upper limit on life expectancy. During the opening session of the symposium, Dr. Buchman observed that “misunderstandings and unknowns lead to beliefs and behaviors around care near the end of life.” The biological intractability of the aging process that was characterized in Dr. West’s work suggests that there is much work to do in helping terminally ill patients to make informed choices.

Joshua Hauser, MD, associate professor of palliative care medicine at Northwestern University’s Feinberg School of Medicine, facilitated a session which focused attention on an underlying psychological issue related

to end-of-life care. Many patients and their families (and a significant number of medical providers) view death as a failure. Human nature likes to win and hates to lose. Palliative care and hospice services are too often viewed as throwing in the towel. Death is equated to losing. Physicians often adopt a “not on my watch” perspective that reinforces the predisposition toward care that Dr. Ely earlier in the day described as “extraordinary or disproportionate.” The Medicare payment system contributes to the psychology of giving up by establishing a sharp line of demarcation between benefits for curative “life-prolonging” care and the hospice benefit. In an effort to establish benefit boundaries to avoid uncontrolled utilization, the Medicare program created unintended consequences. To qualify for hospice benefits, Medicare patients must formally wall themselves off from curative treatments. The arbitrary line of demarcation establishes or reinforces the image of giving up in the minds of patients or their families.

Donald Taylor, Jr., PhD, professor of public policy at Duke University, explored the trade-offs that patients with advanced cancer would make between core medical benefits and quality of life benefits if they were given the choice. In a published study, Duke researchers asked patients with advanced cancer and their caregivers which types of benefits were most important to them. Core medical benefits such as cancer care, primary care, and prescription drugs were evaluated against an array of benefits not currently covered by Medicare, including concurrent palliative care, home-based long-term care, or unrestricted cash – the latter representing an alternative to “cash out,” preserving a portion of the foregone economic expenditures for their families. Interestingly, nearly one in five advanced cancer patients selected all three non-covered benefit types, and those patients allocated twice as much of their “budget” to the non-traditional benefits as they allocated to intermediate or high cancer care. When given the choice, patients and their caregivers reallocated resources from medical care to quality of life enhancing care that is not presently covered by Medicare. The theme that initially emerged early in the symposium – namely that what constitutes the “right” care at the end of life is what a well-informed patient genuinely wants – was echoed during the closing session of the day as Dr. Taylor observed that “patients living with cancer may be the ones most ready to make difficult choices and trade-offs.”

In summary, a number of over-arching themes emerged from a series of provocative discussions facilitated by distinguished thought leaders. There is frequently a lack of connection among terminally ill patients, their families, and medical professionals around facts and expectations. Biological systems work then wear out. Difficult conversations, if they happen at all, often occur too late. When asked, most terminally ill patients express a preference to die at home not in a hospital, yet the majority of deaths occur in hospitals, often in the intensive care unit. As patients decline, it often becomes difficult to accommodate their desire to remain at home, particularly if they lack a strong and available family support system, but there is a wide gap between what patients want at the end of life and what they get...we need to narrow that gap.

The goal of transforming end-of-life care may not involve the provision of any objectively measured “optimal” care in every case. We should redefine success as an incremental increase in the frequency with which what providers do matches what well-informed patients want. Maybe not every terminally ill patient wants to be actively involved in determining their care plan, but many would. Advanced care directives give patients control at a time when their bodies have begun to fail and they have largely lost control. The best chance to fundamentally change end-of-life care rests on local initiatives, involving partnerships between health care providers, patients and their families, social networks, clergy, and community resources, not government policy. Policymakers can take steps to get out of the way, such as by modifying Medicare or Medicaid benefit designs, but the solution must be a grassroots effort, not top-down.

The most important observation related to end-of-life care may have come from Nietzsche nearly 130 years ago: “Those who have a ‘why’ to live for can bear with almost any ‘how’.” Perhaps we need to allow dying patients to be wrong. Take every step possible to arm them with the facts, to ensure that they have all of the information needed to make the best decision...help them toward “right,” but in the end, allow them to be “wrong.” Because when all is said and done, only the patient really knows if we got it right.