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Marshall B. Kapp
Florida State University

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DISTINCTIVE FACTORS AFFECTING THE LEGAL CONTEXT OF END-OF-LIFE MEDICAL CARE FOR OLDER PERSONS

Marshall B. Kapp, J.D., M.P.H.*

INTRODUCTION

Current legal regulation of medical care for individuals approaching the end of life in the United States is predicated essentially on a factual model emanating from a series of high-profile judicial opinions concerning the rights of adults who become either permanently unconscious or are clearly going to die soon with or without aggressive attempts of curative therapy.¹ For jurisprudential pioneers such as Karen Quinlan,² Nancy Cruzan,³ Claire Conroy,⁴ Nancy Jobes,⁵ and more recently Theresa Schiavo,⁶ the questions presented for adjudication revolved around the discrete withholding or withdrawal of specific life-sustaining medical interventions such as artificial feeding, respirators, dialysis, cardiopulmonary resuscitation, or antibiotics.

In many of today's difficult medical situations, however, this prevailing, dramatic pull-the-plug end-of-life paradigm does not fit very neatly.⁷ Key decisions often fall outside the narrow withholding or withdrawing category, as multiple, seemingly non-dramatic but ultimately interconnected, decisions need to be made when the patient's survival and recovery prognosis is uncertain.⁸ As lifespans

*Director, Florida State University Center for Innovative Collaboration in Medicine and Law; Professor at FSU College of Medicine and FSU College of Law; Faculty Affiliate, FSU Claude Pepper Institute and FSU Institute for Successful Longevity.

1. Lois Shepherd, *The End of End-of-Life Law*, 92 N.C. L. REV. 1694, 1716 (2014).

2. *In re Karen Quinlan*, 355 A.2d 647 (N.J. 1976).

3. *Cruzan v. Director, Mo. Dep't. of Health*, 497 U.S. 261 (1990).

4. *In re Conroy*, 486 A.2d 1209 (N.J. 1985).

5. *In re Jobes*, 529 A.2d 434 (N.J. 1987).

6. *See, e.g.*, John A. Robertson, *Schiavo and Its (In)significance*, 35 STETSON L. REV. 101, 120 (2005) (contending that "the Schiavo case is unlikely to change the rules for end-of-life care").

7. Shepherd, *supra* note 1, at 1717.

8. *Id.* Another large area of decision making different from the "pull-the-plug" question concerns patient requests for physician-assisted death (PAD). *Id.* A discussion of PAD issues as they pertain to

increase, death often is preceded by long periods of very gradual decline, chronic illness, and an extension of the dying process,⁹ the timeline of which cannot be predicted with any real precision.¹⁰ For example, “in many cases, the decision about whether or not to attempt to resuscitate a patient may be only a footnote to the overall plan for end-of-life care.”¹¹

The need for a flexible, adaptable approach to medically treating people approaching the end of their lives, and a similar openness to possible modification of the legal framework within which treatment choices are made and implemented, are particularly important when older¹² individuals are involved.¹³ Of the approximately 2.5 million people who die each year in the U.S., about three-quarters of deaths occur among persons aged sixty-five and older.¹⁴ An Institute of Medicine report places these deaths into useful perspective as follows:

In contrast to nonelderly decedents, death among the elderly is most likely to occur after a diagnosis of advanced

older persons is beyond the scope of this article. See Christina White, *Physician Aid-in-Dying*, 53 HOUSTON L. REV. 595, 622–23 (2015); David Orentlicher, *Aging Populations and Physician Aid in Dying: The Evolution of State Government Policy*, 48 IND. L. REV. 111 (2014).

9. Janet L. Dolgin, *Dying Discourse: Contextualizing Advance Care Planning*, 34 QUINNIPIAC L. REV. 235, 247–250 (2016).

10. See Richard Fenigsen, *Other People’s Lives: Reflections on Medicine, Ethics, and Euthanasia*, 28 ISSUES L. & MED. 95, 135 (2012) (“Predicting how long a patient will live constitutes a separate class of obnoxious medical nonsense. Press reports on faulty medical predictions of death have no end.”); J.T. van der Steen et al., *The Difficulty of Predicting Mortality in Nursing Home Residents*, 2 EUR. GERIATR. MED. 79, 80 (2011).

11. Jeffrey P. Burns & Robert D. Truog, *The DNR Order After 40 Years*, 375 N. ENGL. J. MED. 504, 506 (2016).

12. See Sue Westwood, *“I May Be Older, But I Ain’t No ‘Elder’”: A Critique of “Elder Law”*, 21 TEMP. POL. & CIV. RTS. L. REV. 485, 505–06 (2012). In deference to the extreme sensitivity about language on the part of some advocates and commentators, in this article the current politically incorrect terms “elder” and “elderly” will be avoided in favor of the more palatable term “older.” *Id.*

13. Shepherd, *supra* note 1. Shepherd uses the example of President Obama’s 86-year-old mother and her decision to undergo hip replacement surgery after a fall had caused a hip fracture, despite her physicians’ predictions that she was going to die shortly because of terminal cancer. *Id.* at 1717–18.

14. COMM. ON APPROACHING DEATH, INSTITUTE OF MEDICINE, *DYING IN AMERICA: IMPROVING QUALITY AND HONORING INDIVIDUAL PREFERENCES NEAR THE END OF LIFE* 456 (2014) (hereinafter IOM, *DYING IN AMERICA*); see also *Meeting Recap: Assessing Progress in End-of-Life and Serious Illness Care*, NAT’L ACAD. MED., (May 23, 2016), <https://nam.edu/meeting-recap-assessing-progress-in-end-of-life-and-serious-illness-care/> (reporting on an eighteen-month follow-up meeting assessing progress since the 2014 IOM report).

chronic illness as opposed to a sudden, unexpected death. Of all deaths in 2011 among persons aged 65 and older, 26 percent were due to heart disease, 22 percent to cancer, 7 percent to chronic lower respiratory diseases, 6 percent to stroke, and 5 percent to Alzheimer's disease. For the one-quarter of all deaths among the nonelderly, a much larger proportion is due to accidents, homicide, suicide, or acute episodes of illness.¹⁵

As stated succinctly by historian Jill Lepore, “[t]he longer we live, the longer we die.”¹⁶

This article outlines a few of the most salient clinical and social factors that distinguish the large and growing cohort of older persons,¹⁷ in potentially legally and policy relevant ways, from other population groups for whom end-of-life medical treatment choices may come into play. Some practice and policy implications are alluded to briefly.

DISTINCTIVE CHARACTERISTICS OF END-OF-LIFE MEDICAL TREATMENT DECISIONS FOR OLDER PERSONS

1. Prevalence of Cognitive or Affective Impairments and Its Impact on Decision Making

There is a significantly higher prevalence rate of cognitive, and often affective, impairment among older individuals than ordinarily would be found in the younger population.¹⁸ As observed by one commentator:

15. IOM, *DYING IN AMERICA*, *supra* note 14, at 456.

16. JILL LEPORE, *THE MANSION OF HAPPINESS* 159 (2012).

17. *Id.* at 35.

Three times the percentage of Americans pass their 65th birthday today as was the case in 1900, and the proportion of the population reaching age 85 is 48 times larger than a century ago. Indeed, the percentage of Americans over age 65 is on an upward trajectory from 9 percent in 1960 to a projected 20 percent in 2050.

Id.

18. Jalayne J. Arias, *A Time to Step In: Legal Mechanisms for Protecting Those With Declining Capacity*, 39 *AM. J. L. & MED.* 135–36 (2013) (citations omitted).

As society ages, the number of elderly with cognitive deficits will also increase. While cognitive decline is commonly associated with normal aging, an additional subset of the population experiences an increased burden of cognitive and functional deficits resulting from neurodegenerative conditions. Age-associated neurodegenerative diseases include Alzheimer's disease, Parkinson's disease, and multiple classes of dementia.¹⁹

Many older persons function adequately for a period of time with mild cognitive impairment.²⁰ However, "functional decline, like cognitive decline, exists on a continuum from healthy aging to dementia."²¹ The higher prevalence of moderate or severe cognitive or affective impairment among older individuals is likely to impact the decision-making process regarding medical treatment near the end of life in several important respects. First, although the ethical principle of autonomy (self-rule) has been firmly embedded as the most important cornerstone of modern American end-of-life jurisprudence,²² older patients likely lack sufficient present capacity to understand, manipulate, and appreciate the significance of information to engage fully autonomously in a rational decision-making process. It has been estimated that seventy percent of older adults facing treatment decisions in end-of-life scenarios are incapable of making those decisions by themselves.²³

A substantial percentage of older persons who lack adequate capacity to make and express their own legally valid decisions all by themselves may be capable of some level of assisted or supported decision making and, therefore, should be encouraged and helped to participate in the decision-making process as extensively as feasible

19. *Id.*

20. Ronald C. Petersen, *Mild Cognitive Impairment*, 364 N. ENG. J. MED. 2227, 2227 (2011); Serge Gauthier et al., *Mild Cognitive Impairment*, 367 LANCET 1262, 1262 (2006).

21. Cutter A. Lindbergh et al., *Functional Disability in Mild Cognitive Impairment: A Systematic Review and Meta-Analysis*, 26 NEUROPSYCHOL. REV. 129, 129 (2016).

22. See generally Kathryn L. Tucker, *Give Me Liberty at My Death: Expanding End-of-Life Choice in Massachusetts*, 58 N.Y.L. SCH. L. REV. 259, 263 (2013/2014).

23. IOM, *DYING IN AMERICA*, *supra* note 14, at 189.

in conjunction with family members or friends.²⁴ Even when the impaired older person is able to participate, to some limited extent, in the decision-making process, the health care team or institution ultimately turn to a substitute decision maker²⁵ for the purpose of obtaining legally valid decisions consenting to or declining particular medical interventions.²⁶ Substitute decision making, either solely by the substitute or on a joint substitute-patient basis, occurs for nearly half of hospitalized older adults.²⁷ The role of substitute decision maker for an incapacitated patient is a difficult emotional and intellectual one under even the best of circumstances.²⁸ Research and experience have revealed problems in the operation of substituted decision making in the end-of-life context, and older people are especially ripe for potential harm when the mechanism fails to work properly and decisions made are not consistent with the patient's wishes or best interests.²⁹ The substitute decision-making process may fail either because the substitute does not know well enough the values and preferences of the patient, the substitute becomes emotionally overwrought and unable to make any decision on the patient's behalf, or the substitute intentionally places its own conflicting interests ahead of those of the patient.³⁰ Thus, improvements in how we select, communicate with, and support substitute decision makers should be a high priority for those

24. Nina A. Kohn et al., *Supported Decision-Making: A Viable Alternative to Guardianship?*, 117 P.A. ST. L. REV. 1111, 1111 (2013).

25. The terms "substitute," "surrogate," and "proxy" decision maker often are used interchangeably, but in some states their meanings are distinguished for specific purposes. *Compare, e.g.*, FLA. STAT. § 765.101(19) (2016) (defining a "proxy" as a person who has not been expressly designated to make health care decisions for a particular incapacitated individual, but who is authorized pursuant to the state's default substitute decision maker statute to make health care decisions for that individual) with FLA. STAT. § 765.101(21) (2016) (defining "surrogate" as someone who is expressly designated by a principal to make health care decisions for the principal).

26. Alexia M. Torke et al., *Scope and Outcomes of Surrogate Decision Making Among Hospitalized Older Adults*, 174 JAMA INTERN. MED. 370, 371 (2014).

27. *Id.* at 374.

28. Yael Schenker et al., *I Don't Want to Be the One Saying 'We Should Just Let Him Die': Intrapersonal Tensions Experienced by Surrogate Decision Makers in the ICU*, 27 J. GEN. INTERNAL MED. 1657, 1657 (2012).

29. *See, e.g.*, David I. Shalowitz et al., *The Accuracy of Surrogate Decision Makers: A Systematic Review*, 166 JAMA INTERN. MED. 493, 493, 495–96 (2006).

30. Douglas B. White, *Strategies to Support Surrogate Decision Makers of Patients with Chronic Critical Illness*, 316 JAMA 35, 35 (2016).

concerned with the rights and well-being of vulnerable elders at a time when they can protect themselves the least³¹ and are “at heightened risk of poor-quality, high-cost end-of-life care” because they “have multiple chronic conditions, functional limitations, and frailty.”³²

Special attention must be devoted to protect the legitimate interests of incapacitated older persons who lack an easily identifiable substitute decision maker because the incapacitated person lacks willing-and-able family members or friends and hence is “unbefriended.”³³ Physician commentator Atul Gawande laments the demise of the extended family and that, in the U.S., “old age and infirmity have gone from being a shared, multigenerational responsibility to a more or less private state—something experienced largely alone or with the aid of doctors and institutions.”³⁴

Dr. Gawande’s pessimism about the devotion and attentiveness of American families’ notwithstanding, many older individuals are likely to have spouses, adult children, and even adult grandchildren who are capable, willing, and available to become involved in supporting or substituting for the patient’s decisions.³⁵ Moreover, older individuals have had a longer time, and more reason because of current or anticipated medical decline, to contemplate a future in which decisions must be made by a substitute acting in place of the individual.³⁶ “The higher rate [among the elderly] of any kind of consideration of end-of-life care reflects age-related increases in the prevalence of chronic illnesses, dementia, other cognitive

31. See, e.g., *id.* at 36–37; Nona A. Kohn, *Matched Preferences and Values: A New Approach to Selecting Legal Surrogates*, 52 SAN DIEGO L. REV. 399, 418–24 (2015); Yael Schenker & Amber Barnato, *Expanding Support for “Upstream” Surrogate Decision Making in the Hospital*, 174 JAMA INTERN. MED. 377, 378 (2014).

32. IOM, DYING IN AMERICA, *supra* note 14, at 38.

33. See generally Denis M. Connor et al., *The Unbefriended Patient: An Exercise in Ethical Clinical Reasoning*, 31 J. GEN. INTERN. MED. 128, 129, 131 (2016); Thaddeus M. Pope, *Legal Briefing: Adult Orphans and the Unbefriended: Making Medical Decisions for Unrepresented Patients Without Surrogates*, 26 J. CLIN. ETHICS 180 (2015).

34. ATUL GAWANDE, BEING MORTAL: MEDICINE AND WHAT MATTERS IN THE END 17 (2014).

35. See Marshall B. Kapp, *Legal Issues in Aging Families*, in HANDBOOK OF FAMILIES AND AGING 387–407 (Rosemary Blieszner & Victoria H. Bedford, eds., 2nd ed. 2012).

36. See Barbara A. Noah & Neal R. Feigenson, *Avoiding Overtreatment at the End of Life: Physician-Patient Communication and Truly Informed Consent*, 36 PACE L. REV. 736 (2016).

impairments, frailty, and disability.”³⁷ Some, but certainly not all,³⁸ older individuals help family members or friends who may eventually act as substitute decision makers by formally documenting, before a crisis has arisen, their future medical treatment values and preferences in written advance instruction directives.³⁹ Research suggests that encouraging the use of electronic patient portals might be one way to improve documentation of advance care planning discussions, at least in “middle-aged and technology savvy older adults.”⁴⁰ Some older persons go further and relieve their families of the decision-making burden altogether by agreeing to have the physician write a Physician Order for Life-Sustaining Treatment (POLST), converting the patient’s future treatment wishes into the actionable format of a physician’s medical orders.⁴¹ Because older persons are the most likely population to suffer from advanced, irreversible illness and frailty, they are the most appropriate candidates for POLSTs.⁴²

Whether or not the patient executes formal advance directives or the physician writes a POLST based on the patient’s agreement, a growing percentage of

[e]lders do engage in [advance care planning] discussions, most often with family present, if given an opportunity to reflect on their goals, values, and beliefs; to articulate and document their treatment preferences; and to choose a

37. IOM, *DYING IN AMERICA*, *supra* note 14, at 144.

38. See Jolien J. Glaudemans et al., *Advance Care Planning in Primary Care, Only for Severely Ill Patients? A Structured Review*, 32 *FAM. PRACTICE* 16, 20 (2015) (finding that only one-third of patients who died non-sudden deaths had executed an advance planning document).

39. See generally Marshall B. Kapp, *Advance Medical Care Planning: The Legal Environment*, in *ADVANCE CARE PLANNING: COMMUNICATING ABOUT MATTERS OF LIFE AND DEATH* 59–73 (Leah Rogne & Susana L. McCune eds., 2014).

40. Seuli Bose-Brill et al., *Factors Associated With Age Affect Willingness to Engage in Early End-of-Life Communications Using Electronic Health Record-Tethered Patient Portals*, 64 *J. AM. GERIATRIC SOC’Y* 88, 89 (2016).

41. Robert B. Wolf et al., *The Physician Orders for Life-Sustaining Treatment (POLST) Coming Soon to a Health Care Community Near You*, 40 *ACTEC L.J.* 57, 57–58 (2014) [Wolf I]; Robert B. Wolf et al., *The Physician Orders for Life-Sustaining Treatment (POLST) Coming Soon to a Health Care Community Near You*, 49 *REAL PROP. TR. & EST. L.J.* 71, 82 (2014) [hereinafter Wolf II].

42. Wolf II, *supra* note 41, at 81–82.

health care agent. Those who have these discussions are almost three times as likely to have their end-of-life wishes both known and followed, and their family members suffer significantly less stress, anxiety, and depression after their loved one's death.⁴³

The content of an older person's advance planning discussions with intended substitute decision makers, as well as with the person's physician and other health care professionals,⁴⁴ frequently is richer because the older person has had a longer lifetime during which to contemplate and develop a coherent set of pertinent values and goals for future medical treatment.⁴⁵ In the absence of a formal advance directive or a POLST written while the older person was still decisionally capable, the substitute decision maker may work with the person's physician to create a POLST reflecting the individual's expressed and inferred values and goals.⁴⁶

2. Venues of Dying

Another distinguishing characteristic of older individuals in the end-of-life context relates to their venue for dying. Regional variations exist, but some national observations are possible. Like younger people, many older patients who die each year in the U.S.—approximately 25 percent in 2009—do so while being treated in an acute care hospital setting, often an intensive care unit of one kind or another, although this percentage appears to be declining.⁴⁷ In the same year, around 28 percent of the older population's deaths took place in nursing homes, 33 percent in private residences, and another

43. Minal S. Kale et al., *End-of-Life Discussions with Older Adults*, 64 J. AM. GERIATR. SOC'Y 1962, 1964 (2016) (finding that 61% of older adults report having discussed their preferences regarding end-of-life medical treatment with someone); see also IOM, *DYING IN AMERICA*, *supra* note 14, at 136 (citations omitted).

44. See Noah & Feigenson, *supra* note 37 (discussing patient-physician communication in the end-of-life context).

45. *Id.*

46. Wolf I, *supra* note 41, at 66.

47. IOM, *DYING IN AMERICA*, *supra* note 14, at 33.

14 percent elsewhere.⁴⁸ The venue where older persons die, as well as the kind and quality of care they enjoy or suffer in those venues, is strongly influenced by the incentives exerted by the public financing programs on which most older persons are dependent.⁴⁹ The influence of the Medicare program on how elders die is discussed below.⁵⁰ Older individuals receiving long-term services and supports in either institutional or home- and community-based settings may be dually eligible for both Medicare and Medicaid;⁵¹ for them, specific state Medicaid provisions may be highly determinative of their dying experience.⁵²

Nursing homes deserve particular attention as a site for older person deaths.⁵³ Nursing homes were the scene not only of 28 percent of older patient deaths in 2001, but they also accounted for 70 percent of people dying with advanced dementia.⁵⁴ Moreover, an estimated 44 to 69 percent of nursing home patients are unable to make their own health care decisions.⁵⁵ Palliative services are delivered to some dying nursing home residents, mainly through their enrollment in hospice programs.⁵⁶ However, for most residents, a combination of general nursing home culture and the characteristics of nursing home residents increases the likelihood that conversations within nursing homes among residents, staff, and families about end-of-life treatment preferences may be poor or non-existent and that

48. *Id.*

49. *Id.* at 16.

50. *See infra* Section 4.

51. KATHERINE YOUNG ET AL., KAISER COMM'N ON MEDICAID AND THE UNINSURED, MEDICAID'S ROLE FOR DUAL ELIGIBLE BENEFICIARIES, KAISER FAMILY FOUNDATION ISSUE BRIEF 3 tbl.1 (2013), <https://kaiserfamilyfoundation.files.wordpress.com/2013/08/7846-04-medicaids-role-for-dual-eligible-beneficiaries.pdf>.

52. *See generally* ERICA L. REAVES & MARYBETH MUSUMECI, KAISER COMM'N ON MEDICAID AND THE UNINSURED, MEDICAID AND LONG-TERM SERVICES AND SUPPORTS: A PRIMER (2015), <http://files.kff.org/attachment/report-medicare-and-long-term-services-and-supports-a-primer>.

53. *Cf.* Susan L. Mitchell et al., *A National Study of the Location of Death for Older Persons with Dementia*, 53 J. AM. GERIATR. SOC'Y 299, 301 tbl.1 (2005).

54. *Id.*

55. Kathleen T. Unroe et al., *The IOM Report on Dying in America: A Call to Action for Nursing Homes*, 16 J. AM. MED. DIRECTORS ASS'N 90, 91 (2015).

56. Hospice services also may be provided in assisted living facilities, private homes, and in-patient hospice facilities. Because hospice services are driven largely by the availability of Medicare payments, hospice is discussed at notes 81–93, *infra*, and accompanying text.

consequently, patient wishes often are not well-respected.⁵⁷ Additionally,

[a]lthough nursing homes typically are a frail elderly person's final residence, federal and state agencies and national accreditation agencies hold them to standards that can be more suitable to life-prolonging than to addressing quality of life and comfort near the end of life. As a result, "evidence indicates that nursing homes undertreat pain, especially in cognitively impaired and minority residents."⁵⁸

For older individuals who die at home, either their own or that of relatives, care often is provided in the final part of life by a combination of formal providers, such as hospice, home health agencies, or independent home care workers, and informal providers, especially family members.⁵⁹ "Family caregivers provide a wide range of essential and increasingly complex services for people with advanced serious illnesses and those nearing the end of life";⁶⁰ they may be paid⁶¹ or unpaid,⁶² but generally this workforce "is invisible; undertrained; and stressed physically, emotionally, and financially."⁶³ As emphasized by the Institute of Medicine:

Given an explicit choice, most people would prefer to spend their last weeks and days in their own home, free of

57. Gail L. Towsley et al., *Conversations About End of Life: Perspectives of Nursing Home Residents, Family, and Staff*, 18 J. PALLIATIVE MED. 421, 421 (2015).

58. IOM, DYING IN AMERICA, *supra* note 14, at 54–55.

59. Noah & Feigenson, *supra* note 36, at 741.

60. IOM, Dying in America, *supra* note 14, at 8.

61. Medicaid's Cash & Counseling program, where available, permits beneficiaries to pay family members for caregiving services using public program dollars. 42 C.F.R. § 441.655 (2015). Family caregivers of seriously injured veterans may receive a stipend under the Veterans Affairs Program of Comprehensive Assistance to Family Caregivers. 38 U.S.C. § 1720G (2012).

62. Marshall B. Kapp, *For Love, Legacy, or Pay: Legal and Pecuniary Aspects of Family Caregiving*, 14 CARE MGMT. J. 205 (2013). The Family and Medical Leave Act of 1993, Pub. L. 103-3 § 102, guarantees up to 12 weeks of job-protected unpaid leave for attending to the care needs of a spouse, child, or parent. 5 U.S.C. § 6382 (2012).

63. IOM, Dying in America, *supra* note 14, at 8.

pain, clean and comfortable, and in control—not in emergency departments, hospitals, and critical care units away from family and familiar surroundings. . . . [N]ew models of home and community health care delivery and improved communication technologies are making that choice increasingly possible; however, adequate support for family caregivers remains an unmet need.⁶⁴

Regardless of the ultimate site of death, many older people experience multiple transitions as they approach the end of life between care settings, including between hospitals and nursing homes or private homes.⁶⁵ Poorly managed transitions between care settings often implicate medication errors, disruptions in care planning, and failures to coordinate care.⁶⁶

Transitions characterized by these deficits or those that are simply difficult for sick, confused patients and their families to manage are considered “burdensome.” Transitions between care settings can be confusing and overwhelming to patients, especially seriously ill patients, and their families and can result in preventable readmissions or emergency department visits. Often, appropriate follow-up referrals are not made, follow-up with relevant health care professionals is not sufficiently timely, psychological and social needs are not addressed, and potentially useful personnel such as social workers, pharmacists, health educators, and rehabilitation therapists are not engaged.⁶⁷

64. *Id.* at 94. Regarding the growth of home- and community-based options for long-term services and supports, see generally Marshall B. Kapp, *Home and Community-Based Long-Term Services and Supports: Health Reform's Most Enduring Legacy?*, 8 ST. LOUIS U. J. HEALTH L. & POL'Y 9 (2014).

65. IOM, *Dying in America*, *supra* note 14, at 53.

66. *Id.*

67. *Id.*

As a result of poorly coordinated care transitions, many older persons experience interventions, especially when they are sent to the hospital emergency department from home or the nursing home, that cause discomfort and produce little meaningful benefit.⁶⁸

3. Existence of an Aging Network

Another distinctive aspect of aging in the U.S. that may exert some impact on end-of-life care and decision making is the existence, under the authorization of the Older Americans Act (OAA), of a National Aging Network to make certain services available to older persons.⁶⁹ The federal Administration on Aging (AoA) awards OAA funds annually to State Units on Aging (SUAs)—generally, state offices or departments of aging—for nutrition and supportive home- and community-based services; disease prevention and health promotion services; elder rights programs, including long-term care ombudsman programs, legal services, and elder abuse prevention efforts; the National Family Caregiver Support Program; and the Native American Caregiver Support Program. States are divided into planning and service areas (PSAs) and the SUA grants OAA funds to the Area Agency on Aging (AAA) designated for each PSA based on the AAA's determination of the needs of older persons in the PSA.⁷⁰

Service agencies that are part of the aging network supported by an AAA with OAA funds may engage in activities relating to the end-of-life medical experiences of older clients.⁷¹ One example could involve older person's rights agencies, particularly long-term care

68. See generally Lisa M. Trahan et al., *Decisions to Transfer Nursing Home Residents to Emergency Departments: A Scoping Review of Contributing Factors and Staff Perspectives*, J. AM. MED. DIRECTORS ASS'N (June 24, 2016), doi:10.1016/j.jamda.2016.05.012; Kevin M. Terrell & Douglas K. Miller, *Challenges in Transitional Care Between Nursing Homes and Emergency Departments*, 7 J. AM. MED. DIRECTORS ASS'N 499 (2006). But see John E. Morley, *Opening Pandora's Box: The Reasons Why Reducing Nursing Home Transfers to Hospital Are So Difficult*, 17 J. AM. MED. DIRECTORS ASS'N 185 (2016).

69. *Administration on Aging, National Aging Network*, U.S. DEP'T OF HEALTH & HUMAN SERV., ADMIN. FOR COMMUNITY LIVING (Aug. 7, 2015), http://www.aoa.gov/AoA_programs/OAA/Aging_Network/Index.aspx.

70. *Id.*

71. *Administration on Aging, Older Americans Act*, U.S. DEP'T OF HEALTH & HUMAN SERV., ADMIN. FOR COMMUNITY LIVING (June 7, 2016), https://aoa.acl.gov/AoA_Programs/OAA/index.aspx.

ombudsmen, engaging in advocacy efforts intended to assist older persons to know and assert their rights within the health care system. Another network service agency might move end-of-life conversation outside the community setting to engage and educate older persons in the community regarding advance medical planning activities, and then facilitate the accomplishment of those planning efforts.⁷² There currently is no counterpart to the OAA-funded National Aging Network or its activities for the younger population.

4. Medicare

Without at all diminishing the importance of the foregoing discussion of distinguishing factors, perhaps the key difference between younger and older people in this country in terms of age's effect on end-of-life medical care and decision making is the existence of the Medicare program. Approximately 80 percent of deaths in the U.S. occur among the roughly 30 percent of the population covered by Medicare,⁷³ the federal program that subsidizes certain health services primarily for older Americans.⁷⁴ Approximately one-quarter of Medicare spending is incurred by individuals in their last year of life,⁷⁵ with some difficult-to-explain differences among racial and ethnic groups.⁷⁶ In short:

[T]he Medicare program is—and will remain—the

72. Kimberlie Flowers & Judith L. Howe, *Educating Aging Service Agency Staff About Discussing End-of-Life Wishes*, 11 J. SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE 147, 149 (2015).

73. IOM, *DYING IN AMERICA*, *supra* note 14, at 16.

74. 42 U.S.C. § 1395(c) (2012). Medicare also subsidizes certain health services, regardless of the patient's age, for recipients of Social Security Disability Insurance (SSDI) and patients with End-Stage Renal Disease (ESRD). *Id.*

75. IOM, *DYING IN AMERICA*, *supra* note 14, at 457. The policy and ethical debate about whether that amount is "too much" is beyond the scope of the present article. *See, e.g., id.* at 270; Peter H. Schuck, *The Golden Age of Aging, and Its Discontents*, 18 ELDER L.J. 25, 54 (2010); Richard L. Kaplan, *Top Ten Myths of Medicare*, 20 ELDER L.J. 1, 1920 (2012) (dispelling the myth that Medicare wastes a lot of dollars paying for futile medical treatment). Interestingly, also there is some limited evidence suggesting a spike in end-of-life medical spending for dogs in the veterinary context. Liran Einav, Amy Finkelstein & Atul Gupta, *Is American Pet Health Care (Also) Uniquely Inefficient?*, 5–6 (Nat'l Bureau of Econ. Research, Working Paper No. 22669, 2016), <http://www.nber.org/papers/w22669>.

76. Elena Byhoff et al., *Racial and Ethnic Differences in End-of-Life Medicare Expenditures*, 64 J. AM. GERIATRIC, SOC'Y 1789 (2016).

predominant payer for end-of-life care in the United States, primarily because of the older ages at which most Americans die. Moreover, Medicare's role in shaping end-of-life care in the United States likely goes beyond the proportion of Americans who die as Medicare beneficiaries, given that older individuals are disproportionately likely to die from advanced illness as opposed to an accident or sudden acute event.⁷⁷

The traditional Medicare program (Medicare Parts A and B) covers a broad range of preventive, acute, and post-acute services.⁷⁸ Medicare Part D covers outpatient prescription drugs.⁷⁹ Most notably for the present discussion, Part A has covered hospice since 1983—with no legislative modifications since then—for individuals with a terminal illness who have an expected prognosis of six months or less and who agree to forego curative treatment for the terminal condition.⁸⁰ A significant and growing number of Medicare beneficiaries are enrolled in Medicare Advantage (Medicare Part C) fee-for-service or managed care plans, which receive a capitated payment from the government to cover all Parts A and B services plus any additional services that the particular plan offers.⁸¹

77. IOM, DYING IN AMERICA, *supra* note 14, at 459. For a broader picture of major health and social programs available to people with serious advanced illnesses, *see id.* at 272–74 tbl.5.1.

78. U.S. DEP'T HEALTH & HUM. SERV., CTR. FOR MEDICARE & MEDICAID SERV., CMS No. 10050, MEDICARE & YOU 2016, (2015) 37, 42, <https://www.medicare.gov/pubs/pdf/10050.pdf> [hereinafter MEDICARE & YOU 2016].

79. *Id.* at 105.

80. *Id.* at 39. However, as geriatrician Muriel Gillick explains:

Some hospices have developed an “open access” model of care, in which they do not require patients to forgo these types of interventions [like blood transfusions, which can be both life-prolonging and comfort-promoting]. Typically they are larger hospices that balance the financial loss they incur from a small number of patients using expensive resources against the profit they earn from a large number of patients with less resource-intensive needs.

Muriel R. Gillick, *How Medicare Shapes the Way We Die*, 8 J. HEALTH & BIOMEDICAL L. 27, 31 (2012). Additionally, even if hospice care has been elected, Medicare will pay for curative care for a condition that is unrelated to the hospice-qualifying diagnosis. MEDICARE & YOU 2016, *supra* note 79, at 39.

81. MEDICARE & YOU 2016, *supra* note 78, at 83.

There are several ways in which present Medicare payment policies impede the provision of optimal medical care, or even affirmatively incentivize inappropriate forms of care, for dying older individuals. Most importantly, “[b]y paying generously for high-tech, hospital-based care, often to the detriment of ‘high touch’ treatment, Medicare has fostered an aggressive approach to end-of-life care.”⁸² The Institute of Medicine stated the problem more expansively:

Although it can be difficult to discern the extent to which financing and payment alone lead to shortcomings in the provision of end-of-life care, researchers and other stakeholders often point to systemic incentives of the traditional Medicare program when discussing challenges such as burdensome, high-intensity treatments delivered at the end of life.⁸³

Part of the frequently excessive aggressiveness of end-of-life treatment for many older patients may be attributed to the set of incentives created by the Medicare program to hospitalize older patients as they closely approach death.⁸⁴ First, even when families want to keep their loved one at home during the dying process and are willing to undertake enormous personal and financial sacrifices as caregivers in order to do so, the needs of the totally dependent dying person may overpower the family’s capacity to maintain the person at home.⁸⁵ The Medicare hospice benefit is underutilized, at least by individuals in traditional Parts A and B Medicare.⁸⁶ “Defining

82. Gillick, *supra* note 80, at 35.

83. IOM, DYING IN AMERICA, *supra* note 14, at 460–61 (citations omitted); *but see id.* at 466: Relative to the traditional Medicare (TM) program . . . , providers serving the nearly 30 percent of beneficiaries enrolled in the Medicare Advantage (MA) program may be better positioned to promote the use of recommended services at the end of life while discouraging the use of unnecessary invasive procedures. MA plans generally are paid on a per-person—rather than a per-service—basis, thereby rewarding plan efforts to manage chronic disease and to minimize unnecessary treatment intensity at the end of life.

84. *Id.* at 466.

85. *Id.* at 51.

86. It may be different when a person is enrolled in a Medicare Advantage plan under Medicare Part C.

hospice eligibility relative to the 6-month prognosis mark can be quite difficult, especially for individuals with noncancer diagnoses [such as Alzheimer's disease⁸⁷]. Moreover, limiting hospice to individuals who agree to forego curative therapies creates an artificial distinction between potentially life-prolonging and palliative therapies and could impede both enrollment and quality of care.⁸⁸ Commentators have suggested modifications to the six-month prognosis certification requirement aimed at increasing hospice enrollment.⁸⁹

Even when an eligible individual is enrolled in a Medicare-financed hospice program, often the enrollment takes place very late in the dying process and the limited amount of services provided by the hospice agency under the Medicare benefit still leaves the family with a substantial caregiving burden.⁹⁰ Medicare pays hospices on a per diem basis, and the hospice is expected to provide, within that present maximum daily amount, all nursing, medical, and ancillary services for the hospice-related diagnosis, including medicines, various therapies, social work, and chaplaincy.⁹¹

The net effect is that families in need of more help than hospice can provide have to transfer a patient to a skilled

[H]ospice is one of the few benefits “carved out” of Medicare’s managed care program. When managed care enrollees enter hospice, [fee-for-service] Medicare becomes the payer for both hospice care and care unrelated to the terminal condition; health plans remain liable only for any supplemental benefits they provide beyond those in [Traditional Medicare], such as vision or dental care. This policy creates a strong financial incentive for plans to promote hospice enrollment among their more expensive terminally ill enrollees.

IOM, DYING IN AMERICA, *supra* note 14, at 466 (citations omitted); *see also* Fairfield et al., *Disparities in Hospice Care Among Older Women Dying With Ovarian Cancer*, 125 GYNECOL. ONCOL. 14, 14 (2012) (finding that, among older women dying with ovarian cancer, those in Medicare managed care plans were more likely to be referred to hospice).

87. *See* Irene E. van de Vorst et al., *Evaluation of Underlying Causes of Death in Patients With Dementia to Support Targeted Advance Care Planning*, 53 J. ALZ. DIS. 117 (2016).

88. IOM, DYING IN AMERICA, *supra* note 14, at 463.

89. Amanda Jacobowski, *Calculating Death: Implications of the Six-Month Prognosis Certification Requirement for the Medicare Hospice Benefit*, 19 ELDER L.J. 187, 214–15 (2011).

90. *Id.* at 193; Eli L. Diamond et al., *Rates and Risks for Late Referral to Hospice in Patients with Primary Malignant Brain Tumors*, 18 NEURO-ONCOL. 78, 78–80 (2016); Fairfield et al., *supra* note 86, at 15.

91. Gillick, *supra* note 80, at 30.

nursing facility, a hospital, or sometimes a hospice residence. The most common scenario is that family members feel overwhelmed and fear that they do not have the skills to address the loved one's needs.⁹²

Despite a continual effort to devise effective alternative payment methodologies, most physicians continue to be compensated by the Medicare program on a fee-for-service basis that rewards the volume, not the quality, of services delivered.⁹³ “Generous fee-for-service payments give physicians incentives to—even in the final weeks of life—provide high-intensity, high-cost services, consult multiple subspecialties, order tests and procedures, and hospitalize patients.”⁹⁴

Exacerbating the suboptimal care situation is the set of incentives that influence nursing homes to transfer acutely ill residents, such as those with fever and chest pain, out of their familiar, comfortable long-term venue to a hospital where death is regarded as failure and a culture of aggressive, curative treatment rather than palliative care is likely to dominate.⁹⁵ The “when in doubt, ship them out” practice of nursing homes is driven in part by the apprehensions of staff and administrators about potential adverse legal consequences,⁹⁶ in terms of medical malpractice claims,⁹⁷ charges of vulnerable adult neglect,⁹⁸ or regulatory sanctions⁹⁹ if the individual dies in the

92. Gillick, *supra* note 80, at 51; *see also* Stephanie L. Jarosek, Tetyana P. Shippee & Beth A. Virnig, *Place of Death of Individuals with Terminal Cancer: New Insights from Medicare Hospice Place-of-Service Codes*, 64 J. AM. GERIATR. SOC'Y 1815, 1815 (2016) (documenting that many hospice patient deaths occur outside of the home).

93. Nicholas Hodges, *Accountable Care Organizations: Realigning the Incentive Problems in the U.S. Health Care System*, 26 U. FLA. J.L. & PUB. POL'Y 99, 100–02 (2015); Gail Wilensky, *Developing a Viable Alternative to Medicare's Physician Payment Strategy*, 33 HEALTH AFF. 153, 153 (2014).

94. IOM, *DYING IN AMERICA*, *supra* note 14, at 276.

95. Gillick, *supra* note 80, at 52; *see also* Jessica Mantel, *Spending Medicare's Dollars Wisely: Taking Aim at Hospitals' Cultures of Overtreatment*, 49 U. MICH. J.L. REFORM 121, 121 (2015).

96. Regarding legal apprehensions in nursing homes, *see* Marshall B. Kapp, *Legal Anxieties and End-of-Life Care in Nursing Homes*, 19 ISSUES L. & MED. 111, 114 (2003).

97. Anthony M. Carr, *The Wavering Line Between Medical Malpractice and Ordinary Negligence in Elder Abuse Litigation*, 19 HAWAII B.J. 81 (2015); Marshall B. Kapp, *The Liability Environment for Physicians Providing Nursing Home Medical Care: Does It Make a Difference for Residents?*, 16 ELDER L.J. 249, 253 (2009); Saul G. Gruber & Victoria Schall, *Nursing Home Litigation and New Jersey*, 289 N.J. LAW. 72 (Aug. 2014).

98. Katherine Anne Meier, *Removing the Menacing Specter of Elder Abuse in Nursing Homes through Video Surveillance*, 50 GONZ. L. REV. 29, 30 (2014–2015).

nursing home. Nursing homes also are concerned about negative statistics about in-facility resident deaths becoming publicly available and therefore hurting the facility's marketing efforts in a competitive environment.¹⁰⁰ Some resident deaths occurring in nursing homes surely are avoidable with better care, but many are inevitable and indeed welcomed by the resident and family.¹⁰¹

Other incentives to hospitalize a resident who appears to be doing precariously medically are more directly financial.¹⁰² Specifically, most custodial nursing homes are paid for not by Medicare,¹⁰³ but rather by state Medicaid programs, at rates set virtually unilaterally by each state and which inevitably are deemed insufficient by nursing homes and Medicaid-eligible consumers.¹⁰⁴ Consequently, when a resident becomes acutely ill and needs extensive services, the nursing home has an incentive to cost shift to the hospital, which is paid by Medicare for that person.¹⁰⁵ Moreover, when a person is transferred, or transferred back, from the hospital to the nursing home for post-acute skilled nursing or skilled therapy care, that patient is not eligible to simultaneously receive hospice benefits,¹⁰⁶ but the nursing home can then bill Medicare for up to one-hundred days for post-acute services provided to the readmitted resident. The Medicare

99. Harvey M. Tettlebaum, *Quality Measurements, Payment, and the Law: Disincentives to Physician-Patient Discussions of End-of-Life Care*, 6 J. HEALTH & LIFE SCI. L. 63, 76 (2013).

100. See generally Kerry Koehler, *Comparative Shopping in Nursing Homes*, 11 J. HEALTH & BIOMEDICAL L. 439, 448, 466, 470 (2016).

101. Daniel Simmons-Ritchie & David Wenner, *Failing the Frail: Bad Care Leads to Dozens of Avoidable Deaths in Pa. Nursing Homes*, PENN LIVE (Aug. 2, 2016), http://www.pennlive.com/news/page/failing_the_frail_part_1.html#incart_big-photo.

102. David C. Grabowski et al., *Predictors of Nursing Home Hospitalization*, 65 MED. CARE RES. & REV. 3, 30–32 (2008).

103. In nursing homes, Medicare only pays for post-acute care—for example, rehabilitative services following at least a three-day acute hospitalization—for no more than one-hundred days per spell of illness. 42 U.S.C. § 1395d(a)(2)(A) (2012); MEDICARE & YOU 2016, *supra* note 78, at 41; Rachel A. Polzin, *Short-Stay, Under Observation, or Inpatient Admission?—How CMS' Two Midnight Rule Creates More Confusion & Concern*, 8 ST. LOUIS U.J. HEALTH L. & POL'Y 147, 180 (2014).

104. Brietta R. Clark, *Medicaid Access, Rate Setting and Payment Suits: How the Obama Administration is Undermining Its Own Health Reform Goals*, 55 HOWARD L.J. 771, 796–805 (2012). But see *Armstrong v. Exceptional Child Ctr., Inc.*, 135 S.Ct. 1378, 1381 (2015) (holding that a service provider may not challenge the state's Medicaid payment rate); Felicia Sze et al., *Medicaid Rate Challenges Before and After Armstrong v. Exceptional Child Center, Inc.*, 28 HEALTH LAW. 16, 18 (Feb. 2016).

105. Gillick, *supra* note 80, at 52.

106. *Id.* at 52–53.

payment for those post-acute services is substantially higher than the rate Medicare was paying for that resident prior to the hospitalization and return to the nursing home.¹⁰⁷

Another factor driving nursing home behavior is the bed-hold programs enacted by many states with the intent of providing continuity of care for Medicaid beneficiaries who are temporarily transferred to a hospital for an acute problem.¹⁰⁸ Reimbursements “made to nursing homes for days that residents are hospitalized may influence facilities’ propensity to hospitalize occupants.”¹⁰⁹ Further, state Medicaid bed-hold policies also affect the rehospitalization of Medicare post-acute short-stay residents—namely, the more generous the policy, the greater the rate of rehospitalization.¹¹⁰

Despite the perverse Medicare incentives just enumerated, Medicare also creates—and could do even better at creating—potentially positive incentives for better end-of-life care.¹¹¹ For a number of years, patient advocates and commentators have urged that Medicare payments be made available to physicians for conducting conversations with their older patients about advance health care planning.¹¹² A 2009 proposal to include such payments in the Affordable Care Act (ACA)¹¹³ bill, then working its way through Congress, became hopelessly mired in a public “Death Panel” controversy¹¹⁴ and several post-ACA legislative proposals to achieve

107. *Id.* at 52.

108. Grabowski et al., *supra* note 102, at 31–32.

109. Mark Aaron Unruh et al., *Medicaid Bed-Hold Policies and Hospitalization of Long-Stay Nursing Home Residents*, 48 HEALTH SERV. RES. 1617, 1617 (2013).

110. David C. Grabowski et al., *Medicaid Bed-Hold Policy and Medicare Skilled Nursing Facility Rehospitalizations*, 45 HEALTH SERV. RES. 1963, 1963 (2010).

111. Bill Novelli & Raca Banerjee, *Advanced Illness Care: We Can Do Better*, 39 GENERATIONS 106, 107–08 (Summer 2015).

112. *E.g.*, Sara Keary & Sara M. Moorman, *Patient-Physician End-of-Life Discussions in the Routine Care of Medicare Beneficiaries*, 27 J. AGING & HEALTH 983, 983–84 (2015).

113. The Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119 (2010), was amended by the Health Care and Education Reconciliation Act of 2010, Pub. L. No. 111-152, 124 Stat. 1029 (2010), to create the Affordable Care Act.

114. Sarah Palin, *Statement on the Current Health Care Debate*, FACEBOOK (Aug. 7, 2009, 1:26 PM), <https://www.facebook.com/notes/sarah-palin/statement-on-the-current-health-care-debate/113851103434>; Elizabeth Weeks Leonard, *Death Panels and the Rhetoric of Rationing*, 13 NEV. L.J. 872, 872 (2013).

this end also received inadequate support.¹¹⁵ Subsequently, the American Medical Association and other lobbyists turned their efforts toward regulatory activity, asking the Centers for Medicare and Medicaid Services (CMS) to adopt two new billing codes that would pay physicians for time spent discussing advance planning with Medicare patients.¹¹⁶ In response, CMS proposed two new payment codes in July 2015 allowing for physician reimbursement either “in conjunction with Evaluation and Management services or as an optional component of the annual wellness visit.”¹¹⁷ Final regulations were published on November 16, 2015.¹¹⁸

Currently, Medicare is practically the only third-party payer that compensates physicians for conversing with patients about advance health care planning.¹¹⁹ Whether this regulatory foray will be broadly embraced by the public¹²⁰ and whether it will bear fruit in terms of significantly changing physician and patient behavior in ways that really make a salutary difference in end-of-life care for older persons is an empirical question that will need to be researched.¹²¹ A few private insurance companies have experimented with their own billing codes to cover the cost of end-of-life conversations,¹²² but there has been no large-scale indication yet that other private insurers

115. Dolgin, *supra* note 9, at 279–80.

116. *Id.* at 280–81.

117. *Id.* at 281–83.

118. Medicare Program; Revisions to Payment Policies under the Physician Fee Schedule and Other Revisions to Part B for CY 2016, 80 Fed. Reg. 70, 886, 955–60 (Nov. 16, 2015).

119. See Barbara Ostrov, *Doctors Unsure About How to Talk With Patients About End-Of-Life Care*, NPR (Apr. 15, 2016, 10:54 AM), <http://www.npr.org/sections/health-shots/2016/04/15/474267680/doctors-unsure-about-how-to-talk-with-patients-about-end-of-life-care>.

120. See Catherine L. Auriemma et al., *Public Opinion Regarding Financial Incentives to Engage in Advance Care Planning and Complete Advance Directives*, AM. J. HOSPICE & PALLIATIVE MED., June 1, 2016, at 6, <http://ajh.sagepub.com/content/early/2016/05/31/1049909116652608.full.pdf+html> (finding “less than a quarter of Americans support paying physicians when their patients complete advanced directives, and even fewer support paying physicians to discuss advance care planning with patients”).

121. See Alexandra Dansicker, *Paying Docs for End-of-Life Discussions: Can Monetary Incentives Change the Failures Inherent With Physician-Patient Communication?*, 9 ST. LOUIS U.J. HEALTH L. & POL’Y 149, 160–72 (2015) (predicting little impact because of continued problems with communication failures, cultural inhibitions, physicians’ locus of control and patient obedience, the technological imperative in medicine, and reliance on flawed legal instruments).

122. Vanessa Cavallaro, *Advance Directive Accessibility: Unlocking the Toolbox Containing Our End-of-Life Decisions*, 31 TOURO L. REV. 555, 580 (2015).

or state Medicaid plans will follow this lead and financially facilitate advance health care planning for younger individuals.

5. *Ageism Versus Age-Appropriate Considerations in Treatment*

In many situations entailing medical decision making, the patient's age ought to be an important factor taken into account in determining the most appropriate intervention. Age may be relevant to the particular patient's values and preferences, as well as outcome probabilities, and therefore should properly impact that patient's informed choices about alternative approaches to medical care.¹²³ For example, one set of investigators lament their finding that advanced age and prognosis do not appear to be associated with the intensiveness of treatment for keratinocyte carcinoma; these authors submit that, although intensive treatment of symptomatic skin cancer may be indicated, older persons with limited life expectancy should be presented with relevant age-related information to ensure that their treatment is consistent with their goals and preferences.¹²⁴ When the process of physician-patient communication does not adequately include attention to age-related values, preferences, and outcome prognosis, the older patient is at risk of inappropriate treatment,¹²⁵ especially when multiple co-morbidities, disability, and frailty are present.¹²⁶

In other situations though, the older patient's clinical status and prognosis and her personal values and preferences are not de facto determinative of medical decisions for that individual.¹²⁷ Instead,

123. See Bjoerg Thorsteinsdottir et al., *The Ethics of Chronic Dialysis for the Older Patient: Time to Reevaluate the Norms*, 10 CLIN. J. AM. SOC'Y NEPHROL. 2094 (2015). See also Tomasz Beben & Dena E. Rifkin, *The Elderly Are Different: Initiating Dialysis in Frail Geriatric Patients*, 28 SEM. DIALYSIS 221 (2015).

124. Eleni Linos et al., *Skin Cancer in U.S. Elderly Adults: Does Life Expectancy Play a Role in Treatment Decisions?*, 64 J. AM. GERIATRIC SOC'Y 1610, 1610 (Aug. 2016).

125. Jane O. Schell & Robert A. Cohen, *A Communication Framework for Dialysis Decision-Making for Frail Elderly Patients*, 9 CLIN. J. AM. SOC'Y NEPHROL. 2014, 2017 (2014).

126. Kui Hu et al., *Therapeutic Decision-Making for Elderly Patients With Symptomatic Severe Valvular Heart Diseases*, 57 INT. HEART J. 434, 434 (2016); Antonio Teixeira et al, *Management of Acute Health Failure in Elderly Patients*, 109 ARCH. CARDIOVASC. DIS. 422, 423 (2016).

127. Phoebe W. Williams, *Age Discrimination in the Delivery of Health Care Services to Our Elders*, 11 MARQ. ELDER'S ADVISOR 1, 21–22 (2009).

older individuals may experience care that is compromised in some way mainly as a result of negative professional or societal understanding and attitudes about older people and their social value—the phenomenon of ageism.¹²⁸ Proposals that drew a lot of attention in the recent past calling for an official policy of explicit rationing of limited health resources,¹²⁹ especially in the end-of-life context, exclusively on the basis of the patient’s chronological age largely have been successfully rebutted, even by commentators who acknowledge society’s need to set limits on total health care spending.¹³⁰ Even in the absence of explicit, categorical age-based resource rationing, however, age-related bias on the part of health care professionals and patients’ families can de facto adversely affect the quality of older persons’ end-of-life care,¹³¹ increasing the likelihood of either under-treatment or over-treatment.¹³²

As noted by one legal advocate for older persons:

Discrimination against older patients in the provision of health care occurs at the bedside through particular decisions made in the care of an individual patient At the individual level, differential treatment often reflects prejudices and assumptions about older adults, their choices for treatment, and their ability to tolerate and respond to treatment if it is provided.¹³³

For instance, physicians Riou and Boddaert admit:

128. *Id.* at 12–13.

129. *E.g.*, Daniel Callahan, *Must We Ration Health Care For the Elderly?*, 40 J. L., MED. & ETHICS 10 (2012); NORMAN DANIELS, *JUST HEALTH CARE* (1985) (making a “fair innings” argument); DANIEL CALLAHAN, *SETTING LIMITS: MEDICAL GOALS IN AN AGING SOCIETY* (1987).

130. *See, e.g.*, Michael K. Gusmano, *Is It Reasonable to Deny Older Patients Treatment for Glioblastoma?*, 42 J. L., MED. & ETHICS 183, 183 (2014) (answering the title’s question in the negative); David A. Gruenwald, *Can Health Care Rationing Ever Be Rational?*, 40 J. L., MED. & ETHICS 17, 19 (2012).

131. Marshall B. Kapp, *Health Care Rationing Affecting Older Persons: Rejected in Principle But Implemented in Fact*, 14 J. AGING & SOC. POL’Y 27, 30 (2002).

132. Karin M. Ouchida & Mark S. Lachs, *Not Just for Doctors Only: Ageism in Healthcare*, 39 GENERATIONS 46, 47–49 (2015).

133. Michele Mathes, *Health Care and the Aged: Arguing Equality in the Absence of a Right*, 21 TEMP. POL. & CIV. RTS. L. REV. 337, 339–40 (2012) (citations omitted).

[I]ntensivists actually select patients using chronological age, which is clearly not a surprise. The intensivist is not alone in doing so: anesthesiologists, surgeons, and emergency physicians probably do the same. The intensivist conducts admission triage on a daily basis for other patient categories, including younger patients, based on comorbidities, life-expectancy, and expected benefit of ICU. Thus, the right question is the following: Is the selection of elderly patients appropriate? There are many arguments suggesting that decisions may not be appropriate.¹³⁴

Taking the patient's age into proper account in end-of-life treatment decision making—knowing when it is all right and expected for the patient to die, given the medical circumstances—without succumbing to ageism—believing that the patient has consumed a fair share of resources and therefore ought not claim any more—presents a difficult but necessary challenge on the public policy and individual bedside levels.¹³⁵

CONCLUSION

When older people are involved, the end-of-life medical treatment scenario may take on several legally and socially relevant distinct nuances and characteristics. An increased prevalence of cognitive and affective impairments, different venues of dying and transfers among those venues prior to death, the existence of an aging network, incentives and disincentives emanating from the Medicare program, and the tension between appropriate age-related treatment considerations and ageist discrimination against older patients are the

134. Bruno Riou & Jacques Boudaert, *The Elderly Patient and the ICU: Where Are We Going, Where Should We Go?*, 44 *CRIT. CARE MED.* 231, 231 (2015) (citations omitted).

135. See Tobias S. Schiergens et al., *Time-Dependent Impact of Age and Comorbidities on Long-Term Overall Survival After Liver Resection*, *LIVER INT.* (2016), doi: 10.1111/liv.13068; Benjamin Eidelson, *Kidney Allocation and the Limits of the Age Discrimination Act*, 122 *Yale L.J.* 1635, 1638 (2013).

key distinctive features of end-of-life decision making identified in this article. In light of these and other special factors pertinent to older persons approaching the last part of life's journey, flexibility and creativity in the legal and policy approach to end-of-life care in the U.S. will be imperative.