

PANDORA'S DISMAY: ELIMINATING COVERAGE-RELATED BARRIERS TO HOSPICE CARE

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Abstract. Dying Medicare recipients currently must accept the inevitability of impending death before Medicare will fund hospice services. Such a state of affairs is far from optimal, for hospice services provide both physical and psychological benefits long before patients accept their fates. This Article explores the history and philosophy of hospice and highlights the antitherapeutic gap between the time when patients can benefit most from accessing hospice services and the time at which the Medicare statute and regulations first support such access. It concludes by recommending that Congress blur or eliminate the false dichotomy between palliative and curative care that contributes to the gap and calls for empirical research to help determine exactly how Congress should do so.

I. INTRODUCTION

End-of-life medical treatment options represent the ultimate Pandora's box.¹ Upon learning of a terminal or potentially terminal diagnosis, patients act not only out of fear and distress but also out of

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¹ EDITH HAMILTON, *MYTHOLOGY* 88 (1942). Pandora, the first woman the gods created according to Greek mythology, came to Earth as a gift from Zeus. *Id.* She bore a box the gods had forbidden her to open, but “[s]he *had* to know what was in the box.” *Id.* When Pandora succumbed to her curiosity and opened the box, “out flew plagues innumerable, sorrow and mischief for mankind.” *But see id.* (noting this is only one version of the Pandora fable; the other blames Pandora for bringing all misfortune to the world not through her curiosity but through her wicked nature as a woman, for, according to that version of the myth, women “are an evil to men, with a nature to do evil”).

curiosity, seeking to learn more about their conditions in the belief that learning more will lead them toward survival.² They typically explore every possible avenue of treatment, researching all available resources with the expectation and hope there is good news to be found.³ Patients access the Internet, call friends and family members, join support groups, and seek second and third opinions to find good news⁴—much as Pandora opened her box to access what she anticipated were riches within. Eventually however, most patients—some sooner than others—with such diagnoses understand their prospects are bleak.⁵ They did not, in their searches, unleash a variety of ills upon all of mankind, as Pandora did in opening her box,⁶ but their dismay when confronting and then accepting their fates parallels what Pandora experienced upon realizing what she did to mankind.⁷ The difference is that there is often a much longer period of time between the day patients begin with great expectations and the day they experience devastation compared to the period of time it took Pandora first to expect riches and then to appreciate the misfortune in the box.

Currently, most dying patients must progress through this entire range of emotions before payors will cover hospice services.⁸ By statutory and regulatory fiat, Medicare requires that patients renounce all

² See Kathy L. Cerminara, *Dealing With Dying: How Insurers Can Help Patients Seeking Last-Chance Therapies (Even When the Answer is No)*, 15 HEALTH MATRIX: J.L.-MED. 285, 288 (2005).

³ See *id.* at 291-92, 315.

⁴ *Id.* at 315.

⁵ See Samira K. Beckwith, *Myths About Hospice*, in MAKING CHOICES: BEGINNING TO PLAN FOR END-OF-LIFE CARE 56, 57 (2002) [hereinafter Beckwith I].

⁶ See HAMILTON, *supra* note 1 (Hamilton noted in the mid-twentieth century, and as is still true, hope “remains to this day mankind’s sole comfort in misfortune”); see also ROBIN HARD, THE ROUTLEDGE HANDBOOK OF GREEK MYTHOLOGY 95 (2004) (in all versions of the Pandora fable, hope remains in Pandora’s box, as the only good Pandora’s actions brought to mankind). For a discussion of hope and terminally ill patients see *infra* notes 105, 107.

⁷ See HAMILTON, *supra* note 1.

⁸ See 42 C.F.R. § 418.24(b)(3), (d)(2) (2009) (stating patients must waive other treatment options before Medicare will fund hospice care). *But see* Patient Protection and Affordable Care Act, H.R. 3590, 111th Cong. § 3140(a) (2010) (establishing, as part of health care reform, a demonstration program “under which Medicare beneficiaries are furnished, during the same period, hospice care and any other items or services covered under [Medicare]”).

curative treatment for their terminal diagnoses before it will pay for hospice services.⁹ In states in which Medicaid covers hospice, Medicaid provisions are to the same effect.¹⁰ Further, some private payors tend to mimic Medicare in this respect as well.¹¹

Such a state of affairs is far from optimal, for hospice services could provide both physical and psychological benefits to patients long before those patients accept their fates and long before they finally decide it is time to stop looking for the *good* in the box. The current state of the law leaves an antitherapeutic gap between the type of care that most dying patients can access and the type of care that would best serve their needs. Gaps between coverage and needed care are not unusual. Such gaps appear regularly in America's health care system,¹² but

⁹ *Id.*; see also KAREN MATHERLEE, NAT'L HEALTH POLICY FORUM, MANAGING ADVANCED ILLNESS: A QUALITY AND COST CHALLENGE TO MEDICARE, MEDICAID, AND PRIVATE INSURERS 4 (2002) ("While hospice itself is a far-reaching concept, the hospice benefit—as offered by public and private insurers—tends to be fairly restrictive.").

¹⁰ See MATHERLEE, *supra* note 9, at 5 (also explaining that hospice services under the Civilian Health and Medical Program of the Uniformed Services (CHAMPUS) and the Veteran's Administration (VA) are similarly limited).

¹¹ See Haiden A. Huskamp et al., *Providing Care at the End of Life: Do Medicare Rules Impede Good Care? A Study of End-of-Life Care Providers Reveals Some Shortcomings*, 20 HEALTH AFF. 204, 209 (2001) ("In the six markets studied, . . . coverage of and eligibility for end-of-life services were similar in most commercial health plans and [fee-for-service] Medicare."). Even when private plans do not explicitly state rules to this effect, they might impose such rules through the utilization of a review process. See *id.*; see also MARK MERLIS, PRIVATE INSURANCE AND END-OF-LIFE CARE 13, 16 (Robert Wood Johnson Found. 2003), available at <http://www.markmerlis.com/publications.htm> (on file with author) (noting studies indicate that very few private plans had a rule requiring patients "receiving hospice care . . . to forgo other types of treatment," but then describing the practice at private insurer Aetna U.S. Healthcare of not explicitly stating such a rule but of following a practice guideline to that effect); cf. Frank K. Abou-Sayf et al., *Study: Hospice Care Can Yield Savings to HMOs, Patients*, HEALTHCARE FIN. MGMT., Aug. 1991, at 84, 85 (encouraging health maintenance organization coverage of hospice care for non-Medicare beneficiaries on the basis of studies regarding Medicare beneficiaries). But see OFFICE OF DISABILITY, AGING & LONG-TERM CARE POLICY, U.S. DEP'T OF HEALTH & HUMAN SERVS., HOSPICE BENEFITS AND UTILIZATION IN THE LARGE EMPLOYER MARKET 3 (2000) (noting only two of nine large employers with benefit plans covering hospice care researchers interviewed used a Medicare-like model).

¹² Cf. Cerminara, *supra* note 2, at 311-12 (suggesting that insurers adopt conflict management techniques in communicating with patients and families fighting life-

this gap in accessible care for dying patients seems particularly tragic because hospice services provide proven, relatively low-cost yet high-value¹³ benefits that easily could enhance the quality of life for many patients.¹⁴

This Article first explores the history and philosophy of hospice as a part of end-of-life treatment. Next, because Medicare rules “are the dominant influence on hospice policies and revenues,”¹⁵ it examines the Medicare payment rules for hospice care. Finally, this Article suggests that Congress should fill the currently existing antitherapeutic gap in coverage by blurring or eliminating the extant false dichotomy between curative and palliative treatment for purposes of Medicare reimbursement. It is impossible at this time to say exactly how to accomplish this goal, for empirical research is necessary. Rather, this Article intends to pave the way for empirical study aimed at improving the care of dying patients through legal development.

threatening illnesses in cases where coverage is not appropriate); William M. Sage, *Managed Care's Crime: Medical Necessity, Therapeutic Benefit, and the Goals of Administrative Process in Health Insurance*, 53 DUKE L.J. 597, 650 (2003) (advocating a therapeutic method of coverage decision-making in the significant number of cases in which the care a physician advocates for may not be medically necessary and thus will not be covered under the patient's insurance policy).

¹³ Katherine Baicker, *Formula for Compromise: Expanding Coverage and Promoting High-Value Care*, 27 HEALTH AFF. 678, 678 (2008) (explaining high-value care is that which produces the “highest benefits relative to costs”).

¹⁴ For much of these same reasons, Daniel Sulmasy has argued for the coverage of hospice care as an essential part of “health care justice.” See Daniel P. Sulmasy, *Health Care Justice and Hospice Care*, HASTINGS CENTER RPT., Mar.-Apr. 2003, at S14, S14.

¹⁵ Huskamp et al., *supra* note 11, at 209.

II. THE PROMISE OF HOSPICE FOR END-OF-LIFE TREATMENT

With roots in the Victorian United Kingdom,¹⁶ hospice represents a subpart of the larger medical field of palliative care.¹⁷ Palliative care physicians and other palliative care providers focus on easing pain and otherwise caring for patients who are nearing the end of life.¹⁸ The emphasis is on making the best of the time remaining for each patient, rather than fighting to continue life at all costs.¹⁹ Yet, despite more than 150 years of historical, empirical,²⁰ and anecdotal²¹ evidence demon-

¹⁶ Lenora Finn Paradis & Scott B. Cummings, *The Evolution of Hospice in America Toward Organizational Homogeneity*, 27 J. HEALTH & SOC. BEHAV. 370, 373 (1986). According to some sources, the first recorded hospice appeared in the mid-1800s, operated by the Irish Sisters of Charity in Dublin. *Id.* But see JOSEPH J. FINS, A PALLIATIVE ETHIC OF CARE: CLINICAL WISDOM AT LIFE'S END 15 (2006) (claiming that hospice care dates back to 1942 in Lyons, France). It is likely, however, that the hospice movement in America had its roots in the Irish Sisters of Charity. See Paradis & Cummings, *supra* note 16. By 1905 St. Joseph's in London, England, an outgrowth of the Irish Sisters of Charity's hospice in Ireland, had come into existence. *Id.* Dame Cicely Saunders took the movement from there, founded St. Christopher's Hospice outside of London, and became a spokesperson for the hospice movement. *Id.* Dame Saunders was influential in bringing the concept to America when she spoke at a conference held at Yale University in 1963. *Id.*; see also Barbara Monroe et al., *St. Christopher's and the Future*, 56 OMEGA 63, 63 (2007) (describing the history of St. Christopher's).

¹⁷ See FINS, *supra* note 16, at 135-37 (describing hospice care as "another dimension of palliation that is often misunderstood").

¹⁸ The World Health Organization (WHO) defines palliative care as being "the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social, and spiritual support is paramount. The goal of palliative care is the achievement of the best quality of life for patients and their families." *Id.* at 16-17 (quoting World Health Organization, WHO Definition of Palliative Care, www.who.int/cancer/palliative/definition/en (last visited April 12, 2010)).

¹⁹ See Samira K. Beckwith, *Florida Hospices: Comfort, Care and Compassion When it is Needed Most*, in MAKING CHOICES: BEGINNING TO PLAN FOR END-OF-LIFE CARE, *supra* note 5, at 48 [hereinafter Beckwith II] (noting that hospice "puts the comfort of the patient first, honors each person's dignity, respects each individual's wishes, and promotes peace of mind and quality of life for the entire family").

²⁰ See, e.g., Alexi A. Wright et al., *Associations Between End-of-Life Discussions, Patient Mental Health, Medical Care Near Death, and Caregiver Bereavement Adjustment*, 300 JAMA 1665, 1668-70 (2008) (noting the results of some empirical studies).

strating the benefits of hospice care, many patients do not access hospice services as early as experts believe they should.²²

A. *Hospice Basics*

Hospices appeared in America in the late 1960s and early 1970s²³ as a reaction to the institutionalized, impersonal way the medical establishment approached death.²⁴ Situating the emergence of hospice in America within the surrounding cultural development gives one a sense of the seismic changes in attitudes about death occurring at that time. In 1969 Elisabeth Kübler-Ross published her seminal work *On*

²¹ See, e.g., ART BUCHWALD, *TOO SOON TO SAY GOODBYE* (2006) (discussing Buchwald's experience with hospice care). Humorist Art Buchwald famously became a spokesperson for hospice after surviving an extended length of time after accessing hospice services. See Jane E. Brody, *A Humorist Illuminates the Blessings of Hospice*, N.Y. TIMES, Jan. 23, 2007, at F7 (also discussing Buchwald's hospice experience).

²² See *infra* Part I.C.

²³ Precise dates vary. See Marilyn J. Field, *How People Die in the United States*, in *DECISION MAKING NEAR THE END OF LIFE: ISSUES, DEVELOPMENTS, AND FUTURE DIRECTIONS* 70 (James L. Werth, Jr. & Dean Blevins eds., 2009) (identifying the first hospice in the United States as being established in 1974); MATHERLEE, *supra* note 9 (dating federal support for hospice to the mid-to-late 1970s); R. Sean Morrison, *Health Care System Factors Affecting End-of-Life Care*, 8 J. PALLIATIVE MED. S-79, S-82 (2005) (identifying the first hospice in the United States as being established in 1974); Paradis & Cummings, *supra* note 16 (dating the first United States hospice to 1974); Gary R. Vandenbos et al., *An Alternative to Traditional Medical Care for the Terminally Ill: Humanitarian, Policy, and Political Issues in Hospice Care*, 37 AM. PSYCHOLOGIST 1245, 1246 (1982) (noting that federal support of hospice began in 1973).

²⁴ See William G. Bartholome, *Physician-Assisted Suicide, Hospice, and Rituals of Withdrawal*, 24 J. L. MED. & ETHICS 233, 234 (1996) ("In large part, the emergence of hospice was a response to a systematic failure by mainstream health care professionals to deal with the problems of the dying."); Field, *supra* note 23 ("By 1980, advocates for dying people and their families had begun to press for changes in this institutional way of death."); Vincent W. Franco, *The Hospice: Humane Care for the Dying*, 24 J. RELIGION & HEALTH 79, 80 (1985) ("The hospice movement evolved as a reaction against . . . dehumanization of the dying, as well as against unnecessary physical pain suffered in terminal illness."); Vandenbos et al., *supra* note 23, at 1245 (suggesting that hospice was in part a reaction to the medical profession's orientation "toward high technology and the single-minded goal of sustaining life rather than toward humane care of dying and incurable patients," but also noting that costs were a concern).

Death and Dying, conceptualizing the dying process as incorporating five psychological stages.²⁵ The first United States court to recognize a right to refuse life-sustaining treatment, the New Jersey Supreme Court, did so in 1976,²⁶ noting the medical profession had already begun to embrace the philosophy that “physicians distinguish between curing the ill and comforting and easing the dying”²⁷ The emergence of hospice, then, is entirely consistent with, and part and parcel of, that era’s advocacy that society recognize death as the final stage of life—not to be feared but to be acknowledged and to be prepared for. Indeed, the push to incorporate hospice care into dying patients’ experiences was virtually part of a countercultural movement,²⁸ with some writers “liken[ing] its emergence to a religious revival.”²⁹

A patient receiving hospice services receives much more than specialized medical care. For example, patients for whom Medicare pays for hospice care³⁰ are entitled to coverage for a vast array of support beyond physician services, nursing care, drugs, and medical supplies; they also receive short-term inpatient³¹ and respite care,³²

²⁵ See generally ELISABETH KÜBLER-ROSS, ON DEATH AND DYING (Taylor & Francis 2005) (1969) (recognizing the five stages as: denial and isolation, anger, bargaining, depression, and acceptance).

²⁶ *In re* Quinlan, 355 A.2d 647, 651 (N.J. 1976). After the removal of her ventilator support, Karen Ann Quinlan lived for more than nine years. Her parents are major hospice supporters, having founded one as part of the Karen Ann Quinlan Memorial Foundation. See Karen Ann Quinlan Memorial Foundation, <http://www.karenannquinlanhospice.org/> (last visited April 12, 2010).

²⁷ *In re* Quinlan, 355 A.2d at 667. The court continued, stating that based upon the record before it, physicians “refuse to treat the curable as if they were dying or ought to die, and . . . have sometimes refused to treat the hopeless and dying as if they were curable.” *Id.*

²⁸ See Bartholome, *supra* note 24 (using the term counter cultural movement to describe the expansion of hospice services in America); see also FINS, *supra* note 16, at 18-19 (noting that this was a contrast to the European vision of hospice care). In America, he explains, the hospice movement was “outside the medical mainstream and a reaction to its excesses, notably the overuse of medical technology[,]” while in Europe (presumably including the United Kingdom) hospice was a part of the communitarian ethic of medicine. FINS, *supra* note 16, at 18-19.

²⁹ Paradis & Cummings, *supra* note 16, at 370.

³⁰ See *infra* Part III (discussing how Medicare pays for the vast majority of hospice care in this country).

³¹ 42 C.F.R. § 418.202(e) (2009).

homemaker and home health aide services,³³ counseling, including the services of social workers,³⁴ and physical, occupational, and speech/language therapy services as appropriate.³⁵ Even outside the realm of Medicare reimbursement, most packages of hospice services include all those components, including in some cases, access to complementary and alternative therapies.³⁶ Advocates describe hospice care as “combin[ing] state-of-the-art medical care with emotional and spiritual reassurance and also provid[ing] practical assistance and companionship.”³⁷ It embraces “a philosophy that seeks to restore dignity and the chance of fulfillment to dying patients.”³⁸

Patients may receive hospice services in a variety of settings. As initially conceived, a hospice was a place—an institution separate and apart from any other type of health care institution.³⁹ The word *hospice* implies a specific location, deriving from two Latin words: *hospis* (host or guest) and *hospitium* (the location of the giving and receiving of hospitality).⁴⁰ However, the original conceptualization of hospice as a freestanding facility proved unworkable in America for various financial and logistical reasons.⁴¹ Thus, home health care agen-

³² This is provided for in § 418.202(e), as specified in § 418.108(b). *Id.*; see 42 C.F.R. § 418.108 (2008).

³³ 42 C.F.R. § 418.202(g).

³⁴ *Id.* § 418.202(d).

³⁵ *Id.* § 418.202(h); see also Samira K. Beckwith, *Medicare Hospice Benefit: Everything You Need to Know*, in MAKING CHOICES: BEGINNING TO PLAN FOR END-OF-LIFE CARE, *supra* note 5, at 51, 52 [hereinafter Beckwith III] (discussing available therapy).

³⁶ See Beckwith II, *supra* note 19, at 50 (describing some of the complimentary services offered in Florida hospices); see also Leila E. Kozak et al., *Use of Complementary and Alternative Medicine (CAM) by Washington State Hospices*, 25 AM. J. HOSPICE & PALLIATIVE MED. 463, 464 (2009) (stating that payors generally do not pay for alternative or complementary treatments offered as part of integrated hospice care).

³⁷ Beckwith II, *supra* note 19.

³⁸ Vandebos et al., *supra* note 23, at 1245.

³⁹ Paradis & Cummings, *supra* note 16, at 370 (analyzing the transformation in the context of identifying organizational models for the provision of hospice care).

⁴⁰ FINS, *supra* note 16, at 14.

⁴¹ See Paradis & Cummings, *supra* note 16, at 374. The National Hospice and Palliative Care Organization (NPHCO). See generally NAT'L HOSPICE & PALLIATIVE CARE ORG., NPHCO FACTS AND FIGURES: HOSPICE CARE IN AMERICA (2008)

cies began providing hospice care with nurses, social workers, and other professionals visiting patients' homes to care for them along with the patient's family or other chosen caregivers, such as close friends.⁴² Today it is most common for patients to receive hospice services within their homes.⁴³ By the early twenty-first century "[p]atients enrolled in hospice [were] more likely to die at home than others."⁴⁴

Patients who are not able to remain at home have institutional options other than freestanding hospices for the provision of hospice care. Hospitals are increasingly devoting sections or at least a certain number of beds to hospice care,⁴⁵ and the same is true in nursing homes.⁴⁶ Hospitals or nursing homes provide palliative care, including hospice services, with their own staffs or they may contract for such services with outside providers, such as the same agencies that provide hospice services to patients at home.⁴⁷

The organizational structure of hospice care also has undergone a change over the roughly forty years during which it has been available in America. Initially, not-for-profit institutions (some religiously affiliated, some not) provided most of the hospice care available.⁴⁸ Over time, particularly since a major shift in the availability of funding oc-

[hereinafter NHPCO Facts], available at http://www.nhpco.org/files/public/Statistics_Research/NHPCO_facts_and_figures.pdf.

⁴² Paradis & Cummings, *supra* note 16, at 374. For a definition of *residential hospice*, see Suzanne S. Prevost & J. Brandon Wallace, *Dying in Institutions, in DECISION MAKING NEAR THE END OF LIFE: ISSUES, DEVELOPMENTS, AND FUTURE DIRECTIONS*, *supra* note 23, at 189, 201.

⁴³ In 2007, 70.3% of hospice care provided was provided at patients' places of residence, meaning "the place the patient calls 'home.'" NHPCO Facts, *supra* note 41, at 6. Approximately forty-two percent of hospice care that year was provided in private residences; the remaining twenty-eight percent of care provided at "home" was provided in nursing homes and other residential facilities. *Id.*

⁴⁴ Field, *supra* note 23.

⁴⁵ See Paradis & Cummings, *supra* note 16, at 375.

⁴⁶ Prevost & Wallace, *supra* note 42, at 197, 200.

⁴⁷ *Id.* at 200 ("Increasingly nursing homes have turned to external palliative care specialists or contracted with outside hospice organizations to provide palliative care to their patients.").

⁴⁸ Paradis & Cummings, *supra* note 16, at 371.

curred,⁴⁹ for-profit institutions increasingly have begun providing hospice services. By October 2008 National Hospice and Palliative Care Organization statistics indicated the market for hospice services was nearly evenly split between for-profit and not-for-profit providers, with governmental providers such as county-run hospices and United States Department of Veterans Affairs medical centers occupying a tiny third category.⁵⁰

Moreover, the identity of the individual practitioners providing hospice care has changed over the years as well. Initially, the hospice movement had religious roots.⁵¹ The Irish Sisters of Charity, for example, operated an early hospice in Dublin, providing comfort and such care as they could for those who were dying in their facility.⁵² In America, hospice had different roots. As a reaction to the technological imperative of the medical establishment and an outgrowth of the patient autonomy movement, it “emerged as a set of services that were delivered outside of the hospital setting and within local communities.”⁵³ Under Medicare regulations, “[h]ospice care means a comprehensive set of services . . . identified and coordinated by an interdisciplinary group to provide for the physical, psychosocial, spiritual, and emotional needs of a terminally ill patient and/or family members, as delineated in a specific patient plan of care.”⁵⁴ Each interdisciplinary group must include a physician, a registered nurse, a social worker, and a pastoral or other counselor.⁵⁵ These individuals must “work together to meet the physical, medical, psychosocial, emotional, and spiritual needs of the

⁴⁹ Medicare rules have changed over the years to eliminate a limit on any one individual’s services, but hospice providers are subject to aggregate caps on amounts they may receive. MEDICARE PAYMENT ADVISORY COMM’N, REPORT TO THE CONGRESS: REFORMING THE DELIVERY SYSTEM 208-09 (2008) [hereinafter MEDPAC], available at http://www.medpac.gov/chapters/Jun08_Ch08.pdf.

⁵⁰ Not-for-profit providers made up 48.6% of hospice providers in 2007, for-profit providers 47.1%, and governmental providers 4.3%. NHPCO Facts, *supra* note 41, at 9.

⁵¹ See FINS, *supra* note 16, at 14-15.

⁵² *Id.* at 15-16. Even a few earlier hospices had religious bases. See Franco, *supra* note 24 (describing a magnificent hospice in Syria in the year 475 and one founded in Rome by a Catholic disciple around the year 485).

⁵³ FINS, *supra* note 16, at 19.

⁵⁴ 42 C.F.R. § 418.3 (2009).

⁵⁵ 42 C.F.R. § 418.56(a)(1) (2009).

hospice patients and families facing terminal illness and bereavement.”⁵⁶

Thus, it is fair to say that hospice services in America today are so unlike those provided in the Victorian United Kingdom that the nuns who originally provided hospice care would blink in surprise. They would recognize the orientation toward compassion, relief of pain, and assistance in coping with the end of life. They likely would not recognize the multidisciplinary team of caregivers working for corporations and primarily visiting patients in their homes. The mission of hospice care remains the same, but differing motivations for the growth of the hospice movement produced a distinct result in America.

B. The Benefits of Hospice Care

Hospice services provide both psychological and physical benefits to far more people than just terminally ill patients—families, friends, and caregivers also benefit when hospice becomes involved in a patient’s care.⁵⁷ Foremost in many minds is the hospice physicians’ dedication to the relief of physical pain.⁵⁸ A study in the 1980s indicated that “[p]hysical pain occur[red] in from 60% to 90% of advanced cancer patients but [was] inadequately controlled in about 25%.”⁵⁹ Since the 1980s both legal and medical professionals have noted the

⁵⁶ *Id.* § 418.56.

⁵⁷ See FINS, *supra* note 16, at 16-17 (explaining the WHO definition of palliative care “broadens the unit of care and suggests that palliative medicine transcends the traditional boundaries of the doctor-patient dyad, both by including the needs of families and by addressing psychological and spiritual needs in addition to clinical ones”); see also Bob Wardwell, *Hospice Does Make a Difference*, 26 HOME HEALTHCARE NURSE 502, 502 (2008) (“Hospice treats the whole person and his or her family.”).

⁵⁸ See Jill Rhymes, *Hospice Care in America*, 264 JAMA 369, 369 (1990) (“It is in the control of physical pain that the hospice movement has had its strongest influence on conventional medical care.”); see also World Health Organization, *supra* note 18 (noting the relief of physical pain first among the goals of such care).

⁵⁹ Rhymes, *supra* note 58 (citing Kathleen M. Foley, *The Treatment of Cancer Pain*, 313 NEW ENG. J. MED. 84, 85 (1985)); see also FINS, *supra* note 16, at 155 (citing a study indicating that fifty-one percent of cancer patients studied suffered from “moderate to severe pain”).

need for better pain management,⁶⁰ accreditation organizations have required more of an emphasis on management of pain when patients are in health care institutions,⁶¹ and medical professionals are generally better at treating pain than they were previously.⁶² Nevertheless, as a general rule, physicians still undertreat pain,⁶³ and patients remain fearful of pain.⁶⁴ Relief of physical pain is an important goal of palliative care, including the provision of hospice services,⁶⁵ so much so that one author described one of the “[b]asic principles of hospice care,” eventually adopted in other care settings, as being the use of “adequate doses of narcotics around the clock to prevent rather than to treat pain.”⁶⁶

In addition, but hardly incidentally, hospice care psychologically benefits patients, families, friends, and caregivers.⁶⁷ Marilyn J. Field

⁶⁰ In the early 1990s, for example, the Mayday Fund began to finance research about pain management and support the development of legal and public resources intended to assist patients in accessing better pain control. *See* The Mayday Fund, Mayday’s Mission, <http://www.maydayfund.org/> (last visited April 12, 2010) (recounting the history of the fund and its mission); *see also* The Mayday Pain Project: About Us, <http://www.painandhealth.org/aboutus.html> (last visited April 12, 2010) (website funded by the Mayday Fund); Mayday Pain Project, http://www.aslme.com/Mayday_Pain_Project (last visited April 12, 2010) (describing joint project of the Mayday Fund and the American Society of Law, Medicine & Ethics to study and propose legal reforms intended to increase access to pain relief).

⁶¹ *See generally* Vida Foubister, *Joint Commission Increases Focus on Pain Management*, AM. MED. NEWS, June 2000, at 11. *See also* *Poor Pain Control No Longer Acceptable Under Joint Commission Pain Standards*, 31 BNA HEALTH L. REP. 1224 (2000).

⁶² The medical community has improved in pain treatment since the late 1980s, largely due to WHO’s global initiative to use opioid analgesics and the United States’ simultaneous attention to cancer pain. *See* Jan Stjernswärd et al., *The World Health Organization Cancer Pain and Palliative Care Program: Past, Present, and Future*, 12 J. PAIN & SYMPTOM MGMT. 65, 67-68 (1996).

⁶³ FINS, *supra* note 16, at 157 (“Although the relief of pain and suffering is accepted as a compelling ethical obligation, we continue to undertreat our patients.”).

⁶⁴ *See generally* Han J.A. Samwel et al., *The Role of Helplessness, Fear of Pain, and Passive Pain-Coping in Chronic Pain Patients*, 22 CLINICAL J. PAIN 245 (2006).

⁶⁵ *See* FINS, *supra* note 16, at 156-59; *see also* Franco, *supra* note 24 (noting “unnecessary physical pain suffered in terminal illness” as one of the motivating factors in the development of hospice care).

⁶⁶ Rhymes, *supra* note 58, at 369.

⁶⁷ *See* FINS, *supra* note 16, at 16-17 (explaining the WHO definition of palliative care “includ[es] the needs of families . . . by addressing psychological and spiritual needs in addition to clinical ones”).

notes that by around 1980, “[h]ospice offered an option that . . . provided patients and family members with more control over decisions at the end of life[.]”⁶⁸ and Mark A. Mesler describes patient control at the end of life as “one of the primary principles of the hospice philosophy.”⁶⁹ Research indicates that patients benefit psychologically from possessing and exercising that control.⁷⁰ Indeed, the Anglo-American medicolegal system’s recognition of the right to refuse even life-sustaining medical treatment revolves around the idea of control, rooted in concepts of autonomy and self-determination.⁷¹ The benefits patients receive from having greater control in the hospice setting not only exist in psychological research, but medical and legal circles also recognize such benefits.

⁶⁸ Field, *supra* note 23.

⁶⁹ Mark A. Mesler, *The Philosophy and Practice of Patient Control in Hospice: The Dynamics of Autonomy Versus Paternalism*, 30 OMEGA 173, 173 (1995).

⁷⁰ See Kathy L. Cerminara & Alina M. Perez, *Therapeutic Death: A Look at Oregon’s Law*, 6 PSYCHOL. PUB. POL’Y & L. 503, 513-15 (2000) (listing ways in which control psychologically benefits patients nearing death). Statistics from the State of Oregon, the first state to legalize physician aid in dying in America, demonstrate that a primary reason patients seek assistance in dying is the desire for control over some aspect of their lives at a time at which their bodies are betraying them. See Death with Dignity Act Annual Reports, Table 1: Characteristics and End-of-Life Care of 460 DWDA Patients Who Died After Ingesting a Lethal Dose of Medication, by Year, Oregon, 1998-2009, <http://www.oregon.gov/DHS/ph/pas/docs/yr12-tbl-1.pdf> (last visited April 12, 2010) (demonstrating that in the years 1998-2008 89.9% of patients requesting prescriptions to end their lives under Oregon’s statutory scheme cited concerns about loss of autonomy as one reason for doing so, while 58.7% cited concerns about loss of control over bodily functions as a reason; in 2009, the figures were 96.6% and 52.5%, respectively); see also William Yardley, *In Washington, First Death Using Assisted-Suicide Law*, N.Y. TIMES, May 23, 2009, at A10, available at 2009 WLNR 9828712 (quoting first patient in Washington to take advantage of that state’s virtually identical law as saying that she chose to end her life pursuant to the law because “I am a very spiritual person, and it was very important to me to be conscious, clear-minded and alert at the time of my death. The powerful pain medications were making it difficult to maintain the state of mind I wanted to have at my death”).

⁷¹ Justice Benjamin Cardozo famously described the doctrine of informed consent in American law as being based in the concept that “[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body.” *Schloendorff v. Soc’y of N.Y. Hosp.*, 105 N.E. 92, 93 (N.Y. 1914). The United States Supreme Court has confirmed that Americans’ right to control their bodies extends to the ability to refuse life-prolonging medical interventions. See *Cruzan v. Dir., Mo. Dept. of Health*, 497 U.S. 261, 262, 270 (1990).

An additional psychological benefit to patients, their families, friends, and caregivers arises from the roles hospice workers play in their patients' lives as they near death. Hospice personnel stress not only physical symptom control but also attention to *total pain*,⁷² or the entire range of problems that patients, family members, friends, and caregivers experience as patients near the ends of their lives.⁷³ As Doctor Jill Rhymes writes:

Counseling and therapy are important to hospice care, as severe illness and death often expose underlying problems and unresolved disagreements in a family. These conflicts may be exacerbated by guilt, resentment, and anger between the care givers and other family members and by physical and emotional stress on the care givers. Hospice programs provide counseling and help in coping with grief, fear, anxiety, and social problems for the patient, care givers, and family.⁷⁴

In other words, social workers and psychological and spiritual counselors are an integral part of the interdisciplinary teams providing hospice care, not because Medicare and other payors will pay for them, but because their involvement is crucial to the hospice philosophy. Social workers in particular are important resources for various psychosocial purposes. They are also “especially well situated to help assess and address the economic burdens imposed by a terminal illness upon the family unit.”⁷⁵ Social workers and other hospice workers help patients “die with dignity,” which “for hospice means removing not

⁷² Rhymes, *supra* note 58.

⁷³ *See id.* at 370.

⁷⁴ *Id.* Hospice personnel thus might serve as valuable resources when hospitals or other health care institutions work with family members through disputes over futility of care, as Professor Rob Gatter noted at the St. Louis University School of Law faculty workshop at which the author presented a draft of this Article. For additional discussion of the problems encountered in such situations with which hospice personnel might be of assistance, see generally Thaddeus M. Pope & Ellen A. Waldman, *Mediation at the End of Life: Getting Beyond the Limits of the Talking Cure*, 23 OHIO ST. J. ON DISP. RESOL. 143 (2007), and see also Cerminara, *supra* note 2.

⁷⁵ FINS, *supra* note 16, at 243 (listing the other functions social workers serve as well).

only the constraints of pain and suffering, but those of organizational rules designed for the staff's convenience rather than the patient's expressions of individuality."⁷⁶ An important part of their task is to teach patients and their families, friends, and caregivers "what to expect in their last days together, and in what ways, medical and otherwise, hospice could help them be in control of their remaining time despite their failing bod[ies]."⁷⁷

Hospice personnel thus act as *guides into death*,⁷⁸ offering information, support, and guidance from the perspectives of persons who are familiar with the dying process. Those who are watching loved ones progress through a terminal illness often need such guides because "[i]n addition to the grief they experience from their loss, many will also feel frustrated by today's complex and impersonal health care system."⁷⁹ Having guides through that system at such a stressful time is a significant benefit, in addition to the lessons hospice personnel provide in coping and communicating.

The roles these *guides into death* play dovetail with the primary emphasis of physicians practicing palliative care (including hospice), which is to improve each patient's quality of life.⁸⁰ *Quality of life* as a

⁷⁶ Mesler, *supra* note 69, at 174.

⁷⁷ *Id.* at 177. When the author's aunt was dying, for example, a hospice chaplain taught the family, by judicious guidance of bedside discussion, that their remaining hours together would be most fruitful if they reminisced about past good times instead of focusing on the patient's condition. Such reminiscences produced smiles, seemed to relieve the patient's physical distress, and gave the other family members present precious memories. With those benefits in mind, the family members were better equipped the next time they approached the patient's bed to guide the discussion themselves in that direction.

⁷⁸ Thanks are due to Sidney Watson for this concept and turn of phrase.

⁷⁹ Beckwith II, *supra* note 19, at 49 ("The current system generally ignores the fundamental relationship between body, mind, and spirit. This view reduces illness to a biological function and treats the body as machinery to be fixed.").

⁸⁰ See Mesler, *supra* note 69 (describing "the hospice philosophy" as intending "to allow patients with a terminal prognosis . . . the highest quality of life in the time which remains"); Ed Edelson, *National Scorecard Ranks Palliative Care Across Country: Availability Varies Widely, and South Comes Out Worst, Researchers Say*, HEALTHDAY, Oct. 2, 2008, available at 2008 WLNR 18723593; see also 2009 MEDICARE HANDBOOK 5-3 (Judith A. Stein & Alfred J. Chiplin, Jr. eds., 2009) [hereinafter MEDICARE HANDBOOK] ("Palliative care is defined as patient and family-

term of art may concern some; persons with disabilities, for example, become wary when courts and public policy advocates consider quality of life in determining whether a patient would have wished to refuse life-sustaining treatment.⁸¹ In the context of a person with a terminal diagnosis, however, the term *quality of life* is not controversial. Improving a dying patient's quality of life is universally seen as a benefit to that patient, and it is generally considered to include the relief of physical pain and a certain amount of attention being paid to the patient's psychological well-being.⁸²

There is even reason to believe that the psychological benefits of hospice care translate into physical benefits that ease the dying process. While relief of physical pain itself is a primary goal of palliative care professionals such as hospice personnel, the relief of psychological suffering has physical health benefits of its own. Blood pressure can rise and fall with the amount of psychological stress an individual is experiencing.⁸³ Agitation occasioned by anxiety can interfere with the effect of prescription medications intended to relieve physical pain.⁸⁴ Undue

centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Throughout the continuum of illness, it involves addressing physical, intellectual, emotional, social, and spiritual needs and facilitates patient autonomy, access to information, and choice." (citation omitted)).

⁸¹ See generally Kathy L. Cerminara, *Critical Essay: Musings on the Need to Convince Some People with Disabilities That End-of-Life Decision-Making Advocates Are Not Out to Get Them*, 37 LOY. U. CHI. L.J. 343 (2006) (describing concerns of some persons with disabilities that their lives will be deemed to be of lower quality than those of persons without disabilities). See also ALAN MEISEL & KATHY L. CERMINARA, *THE RIGHT TO DIE: THE LAW OF END-OF-LIFE DECISIONMAKING* 4-62 (3d ed. Supp. 2008) (contrasting two uses of the term *quality of life* in end-of-life decision-making law).

⁸² See CTR. TO ADVANCE PALLIATIVE CARE & NAT'L PALLIATIVE CARE RESEARCH CTR., *AMERICA'S CARE OF SERIOUS ILLNESS: A STATE-BY-STATE REPORT CARD ON ACCESS TO PALLIATIVE CARE IN OUR NATION'S HOSPITALS* 8, 35 (2008), <http://www.capc.org/reportcard/state-by-state-report-card.pdf>; see also Edelson, *supra* note 80 (discussing the report card and the findings of the research team).

⁸³ See Jerome H. Markovitz et al., *Psychological Factors as Precursors to Hypertension*, 3 CURRENT HYPERTENSION REP. 25, 29 (2001) (explaining that job stress can be a determinant of increasing or decreasing blood pressure).

⁸⁴ See Myra Glajchen, *Chronic Pain: Treatment Barriers and Strategies for Clinical Practice*, 14 J. AM. BOARD FAM. PRAC. 211, 212 (2001) (identifying anxiety as one patient-related barrier influencing pain assessment and treatment).

amounts of anxiety and stress can weaken the body's immune system,⁸⁵ opening the door to opportunistic infections that can cut the patient's life shorter than the terminal disease alone would have.

In short, the positive effects of hospice care are many and varied. Relief of the patient's physical and psychological pain increases his or her quality of life, and patients and their families benefit in various psychological and sociological ways, gaining guidance from hospice personnel as they progress through a frightening experience. In addition, as counterintuitive as it may seem, patients receiving hospice care actually may see their physical conditions improve in some important ways; thus, hospice care eases their paths to death.

C. Despite the Benefits, Many Patients Access Hospice Later than the Time at Which it Would Be Optimal

Despite the multitude of benefits associated with hospice care, most people access hospice services later than experts recommend. Although experts say people need more than three months of hospice care to fully benefit from its holistic, palliative approach,⁸⁶ at least one-third of hospice patients enroll with a week or less left of life.⁸⁷ In 2000 sixty-three percent of patients received hospice care for fewer than thirty days.⁸⁸ Doctor Joseph J. Fins, an international expert in palliative care, states that “[t]his is clearly too short a period to engage in compre-

⁸⁵ See Frances Cohen et al., *Differential Immune System Changes with Acute and Persistent Stress for Optimists vs Pessimists*, 13 *BRAIN, BEHAV., & IMMUNITY* 155, 155 (1999).

⁸⁶ Joan M. Teno et al., *Timing of Referral To Hospice and Quality of Care: Length of Stay and Bereaved Family Members' Perceptions of the Timing of Hospice Referral*, 34 *J. PAIN & SYMPTOM MGMT.* 120, 121 (2007).

⁸⁷ See Field, *supra* note 23, at 71; see also Alexi A. Wright & Ingrid T. Katz, *Letting Go of the Rope—Aggressive Treatment, Hospice Care, and Open Access*, 357 *NEW ENG. J. MED.* 324, 325 (2007) (stating that in 2005 the median stay in hospice was twenty-six days); Bruce Jennings et al., *Access to Hospice Care: Expanding Boundaries, Overcoming Barriers*, *HASTINGS CENTER REP.*, Mar.-Apr. 2003, at S3, S12, available at http://www.thehastingscenter.org/uploadedFiles/Publications/Special_Reports/access_hospice_care.pdf (reporting that in 1998 the median length of stay was 25 days, ranging from 3.5 to 112 days).

⁸⁸ Barbara J. Haupt, *Characteristics of Hospice Care Discharges and Their Length of Service: United States, 2000*, *VITAL & HEALTH STAT.*, Aug. 2003, at 1, 13.

hensive palliative care.”⁸⁹ These statistics raise an important question revolving around why patients enroll in hospice so much later than experts recommend.

One can imagine both patient-driven and provider-driven reasons why patients enroll in hospice services at the time they do. On the patient side, it is possible the patient did not know of the need for hospice services or chose not to access them earlier. Although limited in scope, at least two studies indicate that in some cases, earlier referral to hospice is not possible because of the lack of an early terminal diagnosis.⁹⁰ Medicare will not reimburse for hospice care without a diagnosis that the patient is terminally ill (i.e., the patient has six months or less to live in the usual course of the disease),⁹¹ and a referral would not occur until reimbursement was possible.⁹² Without referrals, most patients cannot, and will not, access hospice services.

⁸⁹ See FINS, *supra* note 16, at 138.

⁹⁰ See Teno et al., *supra* note 86, at 124. The notorious difficulty of predicting that death is likely to occur within six months or less, which is the regulatory definition of terminally ill, undoubtedly contributes to (or perhaps predominantly causes) this delay in referral. See HOSPICE ASS’N OF AM., HOSPICE FACTS & STATISTICS 6 (2008), available at http://www.nahc.org/haa/attachments/facts_stats2008.pdf (discussing the difficulty of predicting death); see also 42 C.F.R. § 418.3(2) (2009) (defining terminally ill); Jennings et al., *supra* note 87, at S37 (stating the “life expectancy of patients is very difficult to predict unless they have solid tumor cancers”). Such a precise diagnosis is so difficult that the National Quality Forum (NQF), in a consensus report, has recommended the less clinical phrase “death within a year would not be surprising” would be more useful than the defined term terminally ill. NAT’L QUALITY FORUM, A NATIONAL FRAMEWORK AND PREFERRED PRACTICES FOR PALLIATIVE AND HOSPICE CARE QUALITY, at VII (2006), available at <http://www.rwjf.org/files/research/txPHreportPUBLIC01-29-07.pdf>. The NQF also recommends that “[h]ealthcare professionals should present hospice as an option to all patients and families when death within a year would not be surprising and should reintroduce the hospice option as the patient declines.” *Id.*

⁹¹ See Jennings et al., *supra* note 87, at S29 (“[I]n 1998, the National Hospice and Palliative Care Organization identified the requirement of a six-months prognosis as the single most important barrier to extending hospice care to more terminally ill Medicare patients.” (citation omitted)); see also MATHERLEE, *supra* note 9, at 7 (criticizing the six-month prognosis requirement).

⁹² Cf. Teno et al., *supra* note 86, at 124; see also Jennings et al., *supra* note 87, at S33. The Jennings article suggests that “adversarial regulatory enforcement” of the Medicare fraud and abuse laws may have a chilling effect on such diagnoses and referrals to hospice. Jennings et al., *supra* note 87, at S33. In that case, the physician

Similarly, on the patient side, studies indicate that a certain percentage of patients refuse hospice services when they first learn that they qualify for payment for them.⁹³ Although small, these studies produced sufficiently reliable data for Doctor Joan M. Teno and her colleagues to acknowledge them as suggesting “that it might not be possible for some dying persons to have been referred at an earlier time point.”⁹⁴ Moreover, anecdotal evidence supports the data—Doctor Sarah Elizabeth Harrington and Doctor Thomas J. Smith interviewed the physicians of such a patient, Mr. L, who had cancer.⁹⁵ Although Mr. L’s oncologist suggested hospice care and a hospice intake worker visited him at home, Mr. L “wanted to continue fighting the disease instead of entering hospice.”⁹⁶ By the time a palliative care specialist saw him, Mr. L had only weeks, or maybe a month to live, and Mr. L only saw the palliative care specialist because the medical house staff called him in when Mr. L entered the hospital.⁹⁷ He refused hospice care “until it was explicitly clarified that there were no further chemotherapy options.”⁹⁸

Patients may refuse earlier access because they are not ready to acknowledge their conditions,⁹⁹ because they fear electing hospice will reduce the quality of their medical care,¹⁰⁰ or because family members convince physicians not to be candid with patients about their prognoses.¹⁰¹ For some patients (or their surrogates if the patients lack deci-

is driving the delay of the diagnosis of the patient as terminally ill, rather than the patient not actually being terminally ill or no one knowing of the condition.

⁹³ See Erica R. Schockett et al., *Late Referral To Hospice and Bereaved Family Member Perception of Quality of End-of-Life Care*, 30 J. PAIN & SYMPTOM MGMT. 400, 404 (2005).

⁹⁴ Teno et al., *supra* note 86, at 124.

⁹⁵ See generally Sarah Elizabeth Harrington & Thomas J. Smith, *The Role of Chemotherapy at the End of Life: “When Is Enough, Enough?”* 299 JAMA 2667 (2008).

⁹⁶ *Id.* at 2667.

⁹⁷ *Id.* at 2668.

⁹⁸ *Id.* at 2672.

⁹⁹ See Beckwith II, *supra* note 19, at 50; see also HOSPICE ASS’N OF AM., *supra* note 90 (citing “reluctance of caregivers, patients, and families to accept a terminal prognosis” as one reason for patients’ delays in accessing hospice care).

¹⁰⁰ See Wright & Katz, *supra* note 87, at 326.

¹⁰¹ Beckwith II, *supra* note 19, at 50. Research indicates this is especially likely to occur among families of certain cultural backgrounds. For various intersections

sion-making capacity), it is not enough to know and accept the truth, even if also recognizing that hospice care can be of high quality; some people believe that, even if the patient's condition requires *palliative* care, *hospice* care is not appropriate until the very end because "that is where you go to die."¹⁰²

On the provider side, there also may be a variety of reasons for tardy referrals. A physician might hesitate to discuss a terminal prognosis with a patient, at least in part because his or her training has focused on curing patients, instilling a belief that to fail to cure is to fail as a professional.¹⁰³ Possibly linked to that fear of failure, Doctor Sherwin Nuland identifies in some physicians a need to control consequences, which results in a need to "exert[] [their] influence over the dying process, which [they do] by controlling its duration and determining the moment at which [they] allow[] it to end."¹⁰⁴ In addition, medical professionals traditionally believed hope was crucial both to a patient's well-being and to palliation in the form of relief of the patient's mental suffering.¹⁰⁵ In this view, telling the truth about a patient's terminal diagnosis not only robs the patient of the hope of successful treatment,¹⁰⁶ but also constitutes poor palliative care.¹⁰⁷ Finally, it is notoriously difficult to determine that a patient has six months or less to live if

between race, class, culture, and access to hospice care, see Alina M. Perez & Kathy L. Cerminara, *La Caja de Pandora: Improving Access to Hospice Care Among Hispanic and African-American Patients*, 10 HOUSTON J. HEALTH L. & POL'Y (forthcoming 2010).

¹⁰² FINS, *supra* note 16, at 135.

¹⁰³ See Jennings et al., *supra* note 87, at S36 (discussing the tendency in American medicine to focus on prolonging life); see also Beckwith II, *supra* note 19, at 50.

¹⁰⁴ SHERWIN B. NULAND, HOW WE DIE: REFLECTIONS ON LIFE'S FINAL CHAPTER 259 (1994).

¹⁰⁵ See Cerminara, *supra* note 2, at 295; see also FINS, *supra* note 16, at 19-20; Jennifer W. Mack et al., *Hope and Prognostic Disclosure*, 25 J. CLINICAL ONCOLOGY 5636, 5636 (2007) ("Physicians and patients alike believe that the best medical communication allows for hope . . ." (citations omitted)).

¹⁰⁶ See Cerminara, *supra* note 2, at 295; Thomas L. Hafemeister & Richard M. Gulbrandsen, Jr., *The Fiduciary Obligation of Physicians to "Just Say No" if an "Informed" Patient Demands Services that are Not Medically Indicated*, 39 SETON HALL L. REV. 335, 339 (2009) (describing an ancient "duty of deceit, which encouraged physicians to conceal the patient's true condition—especially from the patient" (citation omitted)).

his or her disease follows its normal course.¹⁰⁸ Perhaps as a result of any combination of these factors, overestimation of life span remaining is common.¹⁰⁹

Without timely referrals or decisions made by patients and their families to obtain hospice services, patients either will not receive those services or will not receive them in a timely fashion. The result is that many patients suffer more than they must. Earlier access to hospice services, however, is a public good that the law should encourage. If there are methods by which to eliminate legally imposed coverage-related barriers to earlier access, at least in the Medicare system, policy makers should implement them. To understand how to achieve this goal, it is necessary to understand the legally imposed coverage-related barriers.

III. PAYMENT FOR HOSPICE AS END-OF-LIFE TREATMENT

Medicare pays for a considerable amount of hospice in this country.¹¹⁰ The statutes and regulations outlining the requirements for

¹⁰⁷ See FINS, *supra* note 16, at 19-20 (“If palliation was seen as a way to preserve hope, then the truth was the enemy of hope and frequently hidden from the patient’s view.”).

¹⁰⁸ See *id.* at 149-51 (describing difficulties in labeling prognostication as, *inter alia*, “probabilistic and exceedingly difficult,” “far from an exact science,” and “uncertain and open to bias and false hope”); HOSPICE ASS’N OF AM., *supra* note 90 (noting “the difficulty of predicting death”); Beckwith I, *supra* note 5, at 56-57; see also Sarah Hales et al., *The Quality of Dying and Death*, 168 ARCHIVES INTERNAL MED. 912, 917 (2008) (discussing the “quality of dying and death” as “pertain[ing] to the period immediately preceding death, although it is often not possible to identify precisely when the transition to the dying phase occurs” (citation omitted)).

¹⁰⁹ See Wright & Katz, *supra* note 87, at 325-26.

¹¹⁰ In 2008 the Centers for Medicare and Medicaid Services (CMS) reported spending more than \$11 billion on hospice care. See CTRS. FOR MEDICARE & MEDICAID SERVS., U.S. DEP’T OF HEALTH AND HUMAN SERVS., MEDICARE HOSPICE DATA TRENDS: 1998-2008, available at http://www.cms.hhs.gov/Hospice/Downloads/Hospice_Data_1998-2008.zip (last visited April 12, 2010) [hereinafter MEDICARE TRENDS]. Medicare paid for almost 900,000 patients receiving hospice care that year of the approximately 1.2 million patients the National Hospice and Palliative Care Organization reported as receiving hospice care overall. MEDPAC, *supra* note 49, at 217-18; NHPACO Facts, *supra* note 41, at 4. MedPAC estimated in 2008 that hospice payments would account for about 2.3% of overall Medicare spending in fiscal year 2009. MEDPAC, *supra* note 49, at 203.

Medicare payment drive the scope of coverage for many private insurance companies and Medicaid programs.¹¹¹ Therefore, the Medicare statute and regulations are significant to the development of the contours of hospice care.¹¹² In what may be seen as a “which is the chicken and which is the egg” conundrum, the care that providers will provide often echoes that for which payers will pay.¹¹³ Unfortunately, the Medicare statutes and regulations are sources of confusion for many considering the question of whether a patient qualifies for Medicare payment for hospice care.

**A. *What Medicare Covers, What It Does Not Cover,
and the Resulting Confusion***

Medicare currently pays for hospice services only if a terminally ill¹¹⁴ individual foregoes payment for certain other medical services. Specifically, the Medicare statute provides hospice care “*in lieu of certain other benefits*”¹¹⁵ and that Medicare will pay only for “any expenses incurred for items or services . . . which are . . . reasonable and necessary for the palliation or management of terminal illness.”¹¹⁶ The

¹¹¹ See Huskamp et al., *supra* note 11. Perhaps this is in part because of the hospice-based nature of the Medicare regulations themselves. See Melissa D.A. Carlson et al., *Regulating Palliative Care: The Case of Hospice*, 36 J. PAIN & SYMPTOM MGMT. 107, 114 (2008) (explaining that the National Hospice Organization’s accreditation standards for hospice programs “are the backbone of what eventually became the Medicare hospice certification conditions”).

¹¹² See Huskamp et al., *supra* note 11 (“Medicare rules and policies are the dominant influence on hospice policies and revenues because of the high share of Medicare enrollees are hospices.”).

¹¹³ See Carlson et al., *supra* note 111, at 111 (“Regulation, through the Medicare hospice certification process, was strongly associated with the provision of palliative care services to patients and families enrolled with hospice.”); *see also id.* at 114 (“This study found a strong association between regulation, through a voluntary certification process tied to reimbursement, and the delivery of palliative care services, particularly for patients and families cared for by for-profit hospices.”). Elsewhere in the health care system, patients may be discharged from hospitals when the insurer does not find future care to be necessary. See *Corcoran v. United Healthcare, Inc.*, 965 F.2d 1321, 1324 (5th Cir. 1992).

¹¹⁴ 42 C.F.R. § 418.3 (2009).

¹¹⁵ 42 U.S.C. § 1395d(a)(4) (2009) (emphasis added).

¹¹⁶ 42 U.S.C. § 1395y(a)(1)(C) (2009) (emphasis added). *But see* Patient Protection and Affordable Care Act, H.R. 3590, 111th Cong. § 3140(a) (2010) (establishing, as part of health care reform, a demonstration program “under which Medicare

regulations implementing those statutory provisions distinguish between different types of treatment when describing the election statement a patient must complete before Medicare will pay for hospice services.¹¹⁷ The election statement must include, among other things, an acknowledgement from the patient or the patient's authorized decision maker that "he or she has been given a full understanding of the palliative rather than curative nature of hospice care, as it relates to the individual's terminal illness" and that "certain Medicare services . . . are waived by the election [of hospice care]."¹¹⁸ Those services for which patients waive payment are those "related to the treatment of the terminal condition for which hospice care was elected or a related condition."¹¹⁹ In other words, "[t]he hospice benefit is different from all other Medicare benefits in that it does not provide for the curative treatment of illness or injury; rather it is designed for the palliation and management of terminal illness."¹²⁰

The most basic issue raised by the distinction between curative and palliative treatment is determining whether a particular treatment constitutes curative or palliative treatment. Despite its broad phrasing, the term curative treatment is not simply treatment that cures something. The Medicare regulation explicitly notes the services for which patients waive payment (the curative treatment services) are those "*related to the treatment of the terminal condition for which hospice care was elected or a related condition.*"¹²¹ Thus, "[e]lecting hospice care . . . does *not* mean that all curative treatment is waived. Beneficiaries

beneficiaries are furnished, during the same period, hospice care and any other items or services covered under [Medicare]").

¹¹⁷ See 42 C.F.R. § 418.24(b) (2009).

¹¹⁸ *Id.* § 418.24(b)(2)-(3).

¹¹⁹ *Id.* § 418.24(d)(2); see also MEDICARE HANDBOOK, *supra* note 80, at 5-5. The qualifying language in the remainder of this subsection indicates the waiver applies to payment for curative services unless they are provided by the designated hospice, the individual's attending physician if not employed by that hospice, or another hospice under contract with the designated hospice. 42 C.F.R. § 418.24(d). This seems to relate to the fact that curative treatment unrelated to the terminal illness may be funded, and presumably would be provided, by one of those persons.

¹²⁰ MEDICARE HANDBOOK, *supra* note 80; see also Beckwith II, *supra* note 19, at 54 ("Hospice care is available to any patient whose focus of care has shifted from 'cure' to 'comfort.'").

¹²¹ 42 C.F.R. § 418.24(d)(2) (emphasis added).

who elect the Medicare hospice benefit may still receive Medicare coverage for medically reasonable and necessary treatment for diagnoses unrelated to their terminal illness.”¹²² For example, a patient with terminal cancer¹²³ may be receiving hospice services funded by Medicare at the time he or she breaks a leg. Subject to the usual limitations on allowable charges and other general Medicare requirements, Medicare will pay for both the hospice services and the physician or hospital services involved in treating the broken leg.¹²⁴ Similarly, a patient with terminal cancer developing pneumonia can receive both hospice services and antibiotics to cure a bout with pneumonia, using Medicare funds for both.

According to one study, this distinction causes confusion among caregivers for patients with end-stage renal disease (ESRD).¹²⁵ ESRD is kidney failure resulting in the body’s inability to remove toxins from the blood.¹²⁶ Treatment consists of hemodialysis, a process that involves cleansing the blood by running it through a machine external to the body.¹²⁷ While dialysis will cleanse the blood, and as a result, *cure* the condition that would most immediately cause the patient’s death, renal failure remains chronic and may eventually cause death after the blood can no longer be dialyzed effectively.¹²⁸ Thus, dialysis is cura-

¹²² MEDICARE HANDBOOK, *supra* note 80, at 5-3.

¹²³ See Field, *supra* note 23, at 71 (stating the most common diagnosis in hospice patients is cancer); see also Wright & Katz, *supra* note 87 (noting the largest proportion of patients in hospice had cancer, although “dementia, heart disease, and fatal lung conditions” are also becoming more common).

¹²⁴ See MEDPAC, *supra* note 49, at 207.

¹²⁵ Kimberly F. Thompson et al., *Hospice and ESRD: Knowledge Deficits and Underutilization of Program Benefits*, 35 NEPHROLOGY NURSING J. 461, 465 (2008).

¹²⁶ See Sandy J.K. Oestreich, *Rational Nursing Care in Chronic Renal Disease*, 79 AM. J. NURSING 1096, 1098 (1979) (identifying azotemia, or “excess nitrogenous compounds in the blood,” as a symptom of both renal insufficiency and renal failure, leading up to ESRD).

¹²⁷ See NAT’L KIDNEY & UROLOGIC DISEASES INFO. CLEARINGHOUSE, NAT’L INST. OF DIABETES & DIGESTIVE & KIDNEY DISEASES, KIDNEY FAILURE: CHOOSING A TREATMENT THAT’S RIGHT FOR YOU 2-3 (2007), available at <http://kidney.niddk.nih.gov/kudiseases/pubs/pdf/choosingtreatment.pdf>.

¹²⁸ See Dean G. Smith & John R.C. Wheeler, *Switching and the Definition of Modality in End-Stage Renal Disease Treatment*, 25 MED. CARE 1168, 1172-73 (1987) (describing treatment options and progression for ESRD). Dialysis does not actually cure ESRD in the sense of curing it or making the person permanently well,

tive in the immediate sense—eliminating a condition that could cause the patient’s death in short order and permitting the patient to continue to live, even a number of years thereafter—as long as the patient continues dialysis. If a patient is terminally ill due to ESRD, the patient must forego dialysis (or at least Medicare payment therefor) for Medicare to fund hospice services.

While diagnosed with ESRD, however, a person who requires dialysis due to that condition also may be diagnosed as having a distinctly separate terminal condition. In other words, while it is possible that ESRD itself can lead to death,¹²⁹ it is also possible that a patient with ESRD is terminally ill because of another disease such as cancer or Alzheimer’s disease.¹³⁰ In such a case, a patient may elect both hospice services and continue dialysis, all with Medicare payment. In short, Medicare will pay for dialysis (an arguably curative treatment for ESRD) even while paying for hospice services for an individual who is terminally ill with something other than ESRD. However, Medicare will not pay for treatment that is intended to improve or cure the patient’s terminal illness.¹³¹

This rather shaky distinction between curative and palliative treatment leads to the conclusion that, in some circumstances, the distinction rests upon a false dichotomy. Some treatments can be curative in some circumstances and palliative in others. For example, chemotherapy and radiation may be curative if doctors use them to attack a disease, but doctors also may use each to ease pain.¹³² Similarly, a pa-

and thus differs from the administration of antibiotics to cure pneumonia. *See id.* (explaining antibiotics will actually eliminate the disease from the body of a person with pneumonia). Dialysis does, however, make ESRD *better*, at least for a while, thus *curing* the short-term condition of, essentially, blood poisoning from which the patient is suffering, until the next time the patient requires dialysis. *See id.*

¹²⁹ *Id.* at 1173.

¹³⁰ Thompson et al., *supra* note 125, at 463-64.

¹³¹ In hospice jargon, the label for the terminal illness that provided the basis for hospice certification is “the admitting illness.” *See Hospice Care: Many People are Familiar with this Way of Caring for the Dying, but Misconceptions Abound*, HARV. HEALTH LETTER, July 2008, at 4.

¹³² *See* Harrington & Smith, *supra* note 95, at 2669; Wright & Katz, *supra* note 87, at 325 (noting patients’ choices to “opt for palliation from oral chemotherapies”); *cf.* Wright & Katz, *supra* note 87, at 325 (describing “palliation from oral chemotherapies, radiation, antiemetics, or blood transfusions”).

tient with congestive heart failure early in the course of his or her disease progression may have fluids removed from his or her body to achieve a decent state of health and ward off death; however, late in that disease progression, fluids are removed to allow the patient to breathe more easily and be more comfortable.¹³³ While the distinction between curative and palliative treatment is neither simple to understand nor clear cut, it exists for historical reasons that policy makers cannot ignore because the distinction still retains significance today.

B. The Purpose Behind the Medicare Hospice Benefit

The requirement that patients forego curative treatment in exchange for Medicare to fund hospice services is consistent with the reason that Medicare initially began covering hospice services. Hospice became a Medicare-covered benefit in 1983 primarily because Congress saw it as cost effective.¹³⁴ Generally, foregoing expensive curative

¹³³ See Rajnish Mehrotra & Ramesh Khanna, *Peritoneal Ultrafiltration for Chronic Congestive Heart Failure: Rationale, Evidence and Future*, 96 *CARDIOLOGY* 177, 179 (2001).

¹³⁴ Tax Equity and Fiscal Responsibility Act of 1982, Pub. L. No. 97-248, § 122, 96 Stat. 324 (1982). See Lainie Rutkow, *Optional or Optimal?: The Medicaid Hospice Benefit at Twenty*, 22 *J. CONTEMP. HEALTH L. & POL'Y* 107, 114 (2005) (citing legislative history). Congress instituted overall caps on payments for hospice care for this reason as well. MEDPAC, *supra* note 49, at 204, 208-09; Thomas Hoyer, *A History of the Medicare Hospice Benefit*, in *A GOOD DYING: SHAPING HEALTH CARE FOR THE LAST MONTHS OF LIFE* 61, 63 (Joan K. Harrold & Joanne Lynn eds., 1998). See generally Vandenbos et al., *supra* note 23 (describing the Tax Equity and Fiscal Responsibility Act's enactment of a three-year trial of hospice as a Medicare benefit). The same rationale was offered during the introduction of legislation permitting states to choose to fund hospice services through Medicaid. See Rutkow, *supra* note 134, at 117-21. There also is evidence that the emotional and psychological benefits of hospice care were factors in the 1982 legislation. "In 1982, when Congress enacted the Medicare hospice benefit, the issue of providing family support during the death and dying of their loved ones was apparent. Nowhere was this more evident than in the legislative provision that allowed for respite care so that families did not 'burn out' and become unable to provide informal care to the family member who was dying." NAT'L ASS'N FOR HOME CARE & HOSPICE, 2005 LEGISLATIVE BLUEPRINT FOR ACTION 146 (2005), http://www.nahc.org/NAHC/LegReg/05bp/2005_Leg_Blueprint.pdf; see also Rutkow, *supra* note 134 (noting Representative Leon Panetta, who had introduced the bill making hospice a Medicare benefit, as stating the hospice benefit received "broad bipartisan support" for humanitarian reasons). Congress's requirement that covered hospice services include bereavement counseling for family

treatment¹³⁵ in favor of less-intensive hospice services¹³⁶ will reduce overall costs. This certainly was the case initially, when there were caps on the number of days of hospice coverage available to individual patients through Medicare.¹³⁷ In fact, it remains the case today—that Medicare will pay for an unlimited number of days in hospice per patient as long as the physician in charge of the patient’s care recertifies that the patient is terminally ill at set intervals.¹³⁸ While there is no limit on an individual patient’s Medicare-funded days of hospice service, Congress has imposed an overall cap on benefit dollars that can go to any one hospice during a fiscal year, thus ensuring that hospice care costs remain below those of curative treatment.¹³⁹

members after a patient’s death also supports this conclusion. See Tax Equity and Fiscal Responsibility Act of 1982 § 122(dd)(2)(A).

¹³⁵ “In 1999, approximately 28 percent of Medicare spending was used to provide care for beneficiaries in the last year of their lives.” U.S. GOV’T ACCOUNTABILITY OFFICE, REPORT TO THE HONORABLE RON WYDEN, U.S. SENATE, END-OF-LIFE CARE: KEY COMPONENTS PROVIDED BY PROGRAMS IN FOUR STATES 1 (2007), available at <http://www.aahsa.org/WorkArea/DownloadAsset.aspx?id=2960>.

¹³⁶ In 2007 average hospital inpatient charges per day were \$5549, skilled nursing facility charges per day were \$572, and hospice charges per day were \$144. HOSPICE ASS’N OF AM., *supra* note 90, at 19. Merely discussing end-of-life care options seems to correlate with an effect on costs. One recent study indicates that patients with advanced cancer who had discussed end-of-life treatment options with their physicians “were less likely to undergo mechanical ventilator use or resuscitation or to be admitted to or die in an ICU in the final week of life. They were more likely to receive outpatient hospice care and be referred to hospice earlier.” Baohui Zhang et al., *Health Care Costs in the Last Week of Life: Associations with End-of-Life Conversations*, 169 ARCHIVES INTERNAL MED. 480, 482 (2009). Their care costs about \$1876 during the last week of life, as compared with advanced cancer patients who did not have such discussions, whose care costs about \$2917 in the last week of life. *Id.* More important from a value point of view, “[t]here was no survival difference associated with health care expenditures, and patients whose insured health care costs were higher had worse quality of life in their final week of life” generally, according with the findings of a previous study demonstrating that “life-sustaining care is associated with worse quality of death at the [end of life].” *Id.* at 485.

¹³⁷ The Balanced Budget Act of 1997 (BBA) established unlimited coverage for beneficiaries by changing the three previously defined hospice benefit periods to two ninety-day periods, followed by an unlimited number of sixty-day periods. See MedPAC, *supra* note 49, at 207.

¹³⁸ *Id.*; 42 C.F.R. §§ 418.21, 418.24(c) (2009).

¹³⁹ See generally MedPAC, *supra* note 49.

In 2007 and 2008, the Medicare Payment Advisory Commission (MedPAC), a self-regulated federal entity created by the Balanced Budget Act of 1997, studied “[h]ospice payment issues including payment adequacy, definition of the hospice benefit, changing demographics of hospice patients, and the effects of the aggregate cap.”¹⁴⁰ In June 2008 MedPAC issued a *Report to the Congress: Reforming the Delivery System*,¹⁴¹ a chapter of which addressed the Medicare hospice benefit.¹⁴² In the report, MedPAC noted that Medicare expenditures on hospice care increased greatly over the past twenty-five years since the benefit’s inception.¹⁴³ The increase was partially attributable to an increase in the number of beneficiaries accessing hospice, but it was also due to an increased average duration of stay of those beneficiaries.¹⁴⁴ MedPAC noted that “hospices with longer lengths of stay are more profitable, and for-profit hospices have a length of stay about forty-five percent longer than nonprofit hospices.”¹⁴⁵ Thus, it concluded, “These findings suggest the presence of financial incentives in Medicare’s hospice payment system to provide long stays. Such incentives run counter to the intent of Medicare’s hospice benefit—to provide an alternative that is less intrusive and costly than conventional treatment.”¹⁴⁶

Thereafter, MedPAC held public hearings during which its commissioners discussed and heard testimony about the Medicare hospice benefit (among other subjects).¹⁴⁷ MedPAC concluded in its report that it required more data to determine whether the incentives to provide long stays were attributable to the size of the overall cap on expenditures¹⁴⁸ or other factors. During the public hearings, however, discus-

¹⁴⁰ Janet E. Neigh, *MedPAC Examining Medicare Hospice Benefit Reimbursement System*, CARING, Jan. 2008, at 60, available at <http://www.nahc.org/haa/attachments/HF-Jan08.doc>; see also Balanced Budget Act of 1997, Pub. L. No. 105-33, § 4022, 111 Stat. 251 (1997) (creating the Medicare Payment Advisory Commission).

¹⁴¹ MEDPAC, *supra* note 49.

¹⁴² *Id.* at 203-34.

¹⁴³ *Id.* at xv.

¹⁴⁴ *Id.*

¹⁴⁵ *Id.* at xvi.

¹⁴⁶ *Id.*

¹⁴⁷ See hearing schedule at Meeting Search Results, http://www.medpac.gov/meeting_search.cfm?SelectedDate=2008-11-06%2000:00:00.0 (last visited April 12, 2010).

¹⁴⁸ MEDPAC, *supra* note 49, at 203.

sion revolved in part around a consensus for more accountability and oversight of hospice patients' lengths of stay.¹⁴⁹ One of the ways identified to provide for more accountability regarding long-term stays was to "[r]equire [that] all certifications include a brief explanation of clinical basis for prognosis."¹⁵⁰

As a result, in April 2009 the Centers for Medicare & Medicaid Services (CMS) proposed revisions to the regulations governing the Medicare hospice benefit.¹⁵¹ The proposed revisions would affect hospice payment rates, update and clarify definitions of covered services and payment procedures, and make other changes not germane to this Article.¹⁵² One proposed revision and all three areas on which the CMS invited comment without offering proposals, however, illustrate that hospice costs are still of utmost importance to regulators. Without proposing revisions at this time, the CMS sought input on MedPAC recommendations that practitioners provide more documentation showing they actually visited patients when recertifying their terminal conditions, that CMS revise the hospice aggregate cap calculation, and that Medicare begin to pay hospices a sliding scale of reimbursement (greater upon patients' initial admissions and declining as their lengths of stay increase).¹⁵³

¹⁴⁹ James E. Mathews et al., Presentation at the MedPAC Public Meeting: A Critical Evaluation of the Medicare Hospice Benefit 17 (Nov. 6, 2008), *available at* http://www.medpac.gov/transcripts/20081104_Hospice_final_public.pdf; *see also* MedPAC Meeting Brief (Nov. 6, 2008), http://www.medpac.gov/transcripts/20081031_NOV_MTG%20BRIEF_hospice.pdf.

¹⁵⁰ Mathews et al., *supra* note 149; *see also* Transcript of MedPAC Public Meeting 187, 190-91 (Nov. 6, 2008), <http://www.medpac.gov/transcripts/1106-1107MedPAC%20final.pdf>.

¹⁵¹ *See* Medicare Program; Proposed Hospice Wage Index for Fiscal Year 2010, 74 Fed. Reg. 18912, 18917-18 (proposed Apr. 24, 2009) (to be codified at 42 C.F.R. pts. 405, 418).

¹⁵² *See generally id.* at 18912, 18918-20.

¹⁵³ *See id.* at 18912, 18920-22. The CMS did, however, propose one revision immediately in response to MedPAC's findings and recommendations. It noted MedPAC's criticism that "in some cases there was limited medical director engagement in the certification or recertification process. Physicians had delegated this responsibility to the staff involved with patients' day-to-day care and simply signed off on the paperwork. Second, inadequate charting of the patient's condition or a lack of staff training had led some physicians to certify patients who were not truly eligible for Medicare's hospice benefit. Finally, some panelists cited financial

It is thus clear that costs loom large in the debates about Medicare funding of hospice services. Congress initially showed concern about health care costs when it determined that Medicare should fund health care services, and that cost remains an issue of concern for the executive branch as it implements the hospice funding laws. The executive branch worries hospice care has begun to consume more resources than originally intended, and is seeking to reduce the amount of money spent on hospice care. Value should be part of any discussion about costs, with an eye toward funding services that provide the most benefit relative to cost,¹⁵⁴ so any proposal intended to eliminate the currently existing false dichotomy between curative treatment and palliative care must take both cost and value into account. Empirical research into such proposals must do the same.

IV. A THERAPEUTIC PROPOSAL: IMPROVING ACCESS TO HOSPICE BY ELIMINATING LEGAL BARRIERS TO COVERAGE

When applied to health law, therapeutic jurisprudence “asks what legal principles are most beneficial to patient welfare and consistent with the actual experience of being sick.”¹⁵⁵ It thus encourages scholars, advocates, and policy makers to “think instrumentally and empirically about the law, rather than in terms of intrinsic rights or a priori

incentives associated with long-stay patients.” *Id.* at 18918. In response to MedPAC’s call for more “accountability and enforcement related to certification and recertification[.]” the CMS proposed requiring that physicians include a “brief narrative explanation of the clinical findings that support a life expectancy of 6 months or less. This brief narrative should be written or typed on the certification form itself.” *Id.* at 18917-18. The CMS did “not believe that an attachment should be permissible because an attachment could easily be prepared by someone other than the physician.” *Id.* at 18918. Instead, the CMS believed that requiring “a few sentences” would “encourage greater physician engagement in the certification and recertification process by focusing attention on the physician’s responsibility to set out the clinical basis for the terminal prognosis indicated in the patient’s medical record.” *Id.* The comment period ended on June 22, 2009. *Id.* at 18912. And the requirement became final on August 6, 2009. *See* Medicare Program; Hospice Wage Index for Fiscal Year 2010; Final Rule, 74 Fed. Reg. 39384, 39413 (Aug. 6, 2009) (to be codified at 42 C.F.R. pt. 418.22); *see also id.* at 39398-39400 (discussing comments and explaining final regulation).

¹⁵⁴ *See* Baicker, *supra* note 13, at 661.

¹⁵⁵ Mark A. Hall, *Law, Medicine, and Trust*, 55 STAN. L. REV. 463, 466 (2002).

principles.”¹⁵⁶ With roots in mental health law,¹⁵⁷ therapeutic jurisprudence has been applied to a variety of legal disciplines,¹⁵⁸ encouraging empirical behavioral sciences research to examine the effects of laws upon those subject to them. In health law, Professor Mark Hall concluded that “therapeutic goals should be primary considerations in a body of law that arises from and governs a common enterprise whose central objective is individual health and well being.”¹⁵⁹

A therapeutic jurisprudential approach seems especially applicable in the law regulating end-of-life care. As patients approach death and as less can be done for them physically, the emphasis turns to palliation. While palliation certainly involves relief of physical pain, good palliative care practice focuses equally as much on relieving mental suffering on the part of both the patient and the patient’s loved ones.¹⁶⁰ End-of-life law, with its focus on autonomy, emphasizes psychological factors of the patient’s existence, including the desire for control and the need to act in accordance with the patient’s values and beliefs in choosing or refusing to undergo certain treatments near the end of life.¹⁶¹ Much like procedural justice research indicates that those facing a bad outcome will react better to the outcome if they play a meaningful part (have a voice) in the process pursuant to which the outcome is achieved,¹⁶² a therapeutic jurisprudential approach to how and why this country funds hospice care may lead to patients’ handling the dying process better, in the sense of achieving peace with the outcome even if they would have preferred not to die.

¹⁵⁶ *Id.* at 467.

¹⁵⁷ See generally DAVID B. WEXLER & BRUCE J. WINICK, *LAW IN A THERAPEUTIC KEY: DEVELOPMENTS IN THERAPEUTIC JURISPRUDENCE* (1996).

¹⁵⁸ See generally *id.* (including therapeutic jurisprudence pieces from a variety of fields). See, e.g., REHABILITATING LAWYERS: PRINCIPLES OF THERAPEUTIC JURISPRUDENCE FOR CRIMINAL LAW PRACTICE (David B. Wexler ed., 2008) (criminal law); Peggy Fulton Hora et al., *Therapeutic Jurisprudence and the Drug Treatment Court Movement: Revolutionizing the Criminal Justice System’s Response to Drug Abuse and Crime in America*, 74 NOTRE DAME L. REV. 439 (1999) (criminal procedure).

¹⁵⁹ Hall, *supra* note 155, at 468.

¹⁶⁰ See *supra* Part I.B.

¹⁶¹ See *supra* notes 69-70.

¹⁶² See E. ALLAN LIND & TOM R. TYLER, *THE SOCIAL PSYCHOLOGY OF PROCEDURAL JUSTICE* 94-96 (1988).

Thus, toward that end, this Article recommends that it is time to reassess the law that shaped the contours of payment for hospice services, with the therapeutic intention of facilitating earlier patient access to those services. Specifically, this Article primarily proposes that Congress consider blurring or eliminating the false dichotomy between curative and palliative treatment in the law.¹⁶³ Explicit funding of “bridge to hospice” programs or open-access hospice would help blur the false dichotomy in the law regulating coverage for the vast majority of Americans. In addition to or as a part of agency-level reviews of the Medicare hospice payment system currently being conducted,¹⁶⁴ regulators should propose Congress amend the applicable Medicare statutes to that effect or, at a minimum, fund demonstration projects to examine some or all of the following ideas in an attempt to improve end-of-life treatment for terminally ill patients.¹⁶⁵

A. *What Is Wrong with the False Dichotomy*

A prime example of the false dichotomy between curative and palliative treatment is ESRD care.¹⁶⁶ Kimberly F. Thompson and others investigated whether providers’ misunderstandings of the Medicare funding rules contributed to relative underutilization of hospice services by ESRD patients who choose to forego dialysis.¹⁶⁷ They studied regis-

¹⁶³ See MATHERLEE, *supra* note 9, at 3; Wright & Katz, *supra* note 87, at 326 (noting a “disconnect between pre-hospice and hospice care” in the current health care system).

¹⁶⁴ See *supra* text accompanying notes 140-53. MedPAC has noted that further guidance about and clarification of the stage at which hospice admission is appropriate could help improve access to hospice while addressing cost issues. MEDPAC, *supra* note 49, at 233.

¹⁶⁵ A third way to encourage earlier access to hospice care might be suggested as well, and this list is not exhaustive. The third way would not hinge on legal change but would require cooperation within health care facilities. Specifically, it might be possible to alleviate some of the patient-based reasons for tardy access of hospice services by revising the privileges systems at health care facilities. It should be possible for hospice care providers to take part in end-of-life decision-making discussions with patients and their families even before a patient is referred to hospice care, but such participation might require that persons without privileges be permitted to examine the patient or otherwise become familiar with the patient’s case in a manner not currently permitted by internal rules. (The author is grateful to Rob Gatter for this suggestion.)

¹⁶⁶ See *supra* Part II.A.

¹⁶⁷ See generally Thompson et al., *supra* note 125.

tered nurses, nurse managers, and social workers to analyze their levels of knowledge about, among other matters, Medicare's willingness to continue reimbursement for the cost of dialysis treatment while a patient receives hospice services if the patient's terminal disease is something other than the ESRD.¹⁶⁸ They concluded, "Confusion exists when evaluating a patient with ESRD for hospice services. . . . Hospice organizations interpret Medicare regulations differently, making discontinuation of dialysis conditional in some programs, while not a condition in others."¹⁶⁹ To the extent that those informing patients of the availability of hospice believe incorrectly that Medicare would never reimburse dialysis patients for hospice services unless those patients forego dialysis, patients' missed opportunities to access hospice services can be attributed to provider confusion.

In addition to causing confusion among providers, which can impede prompt patient access of hospice services, this false dichotomy also stands in the way of good palliative care. The current system of Medicare payment for hospice services requires patients to progress somewhat far through Kübler-Ross's phases of dying before they are ready to accept the conditions on Medicare funding.¹⁷⁰ Kübler-Ross famously identified five stages of dying: denial and isolation, anger, bargaining, depression, and finally, acceptance.¹⁷¹ Not all patients proceed through all stages¹⁷²—some continue to experience vestiges of earlier

¹⁶⁸ *Id.* at 462-63.

¹⁶⁹ *Id.* at 465.

¹⁷⁰ Some thanatology scholars disagree with Kübler-Ross. See Richard Schulz & David Aderman, *Clinical Research and the Stages of Dying*, 5 OMEGA J. DEATH & DYING 137, 137 (1974) (asserting that data does not support a dying process with stages, but rather a less rigid process that varies from patient to patient); Charles A. Corr, *Coping With Dying: Lessons That We Should and Should Not Learn From the Work of Elisabeth Kübler-Ross*, 17 DEATH STUD. 69, 70 (1993) (describing various criticisms of the Kübler-Ross stages). Given the congruence of the rise of the hospice movement and her work in America, however, it seems especially appropriate to refer to Kübler-Ross's work here.

¹⁷¹ See KÜBLER-ROSS, *supra* note 25, at 34-121.

¹⁷² Of two hundred patients interviewed, most (but not all) "reacted to the awareness of a terminal illness at first with" denial. *Id.* at 34. See generally Paul K. Maciejewski et al., *An Empirical Examination of the Stage Theory of Grief*, 297 JAMA 716 (2007) (studying similar theory of progression among bereaved relatives and similarly noting variations from the norm), available at <http://jama.ama-assn.org/cgi/content/full/297/7/716>.

stages even while moving through later stages¹⁷³—and some never reach acceptance at all.¹⁷⁴ Nevertheless, the five-stage process satisfactorily captures the overall experience of dying and seems especially fitting for use when discussing hospice care since the hospice movement and Kübler-Ross's work arose from the same cultural milieu.¹⁷⁵

In essence, current law requires that a patient proceed all the way to acceptance in Kübler-Ross's phases of dying¹⁷⁶ before Medicare will pay for hospice services. It is only when the patient reaches the stage at which he or she is willing to forego all efforts at curing his or her terminal illness that Medicare will fund the palliative, holistic care hospice provides. Yet most patients, families, friends, and caregivers are likely to benefit from receipt of that care long before the patient reaches acceptance.

For example, Doctor Alexi A. Wright and others demonstrate that patients' qualities of life generally were better the longer they received hospice care.¹⁷⁷ Of note, they state in describing the results of their research, "patients who received less than a week of hospice care had the same quality of life scores as patients who did not receive hospice at all, suggesting that patients benefit more from early hospice referrals."¹⁷⁸ Patients with hospice enrollments of two months or longer

¹⁷³ KÜBLER-ROSS, *supra* note 25, at 35 ("Denial, at least partial denial, is used by almost all patients, not only during the first stages of illness or following confrontation, but also later on from time to time."). Of two hundred terminally ill patients studied, three attempted to deny they were dying until the very end. *Id.* at 36.

¹⁷⁴ *See id.* at 99-100. Kübler-Ross herself says: "If a patient has had enough time . . . and has been given some help in working through the previously described stages, he will reach a stage during which he is neither depressed nor angry about his 'fate.'" *Id.* at 99 (emphasis added). That stage is acceptance. *Id.*

¹⁷⁵ *See supra* text accompanying notes 23-29.

¹⁷⁶ That requirement seems particularly problematic for those who never reach acceptance at all. *See* KÜBLER-ROSS, *supra* note 25, at 99-100.

¹⁷⁷ This is true, except in cases where patients used hospice for less than a week. Wright et al., *supra* note 20, at 1668; *see also* Morrison, *supra* note 23, at S-81 (advocating integration of palliative care with life-prolonging treatment because such an approach "is associated with reduced suffering, improved satisfaction, reduced hospital costs, and improved transitions through the stages of a progressive illness" (citations omitted)).

¹⁷⁸ Wright et al., *supra* note 20, at 1670.

had quality of life scores more than a full point higher than these patients, on a ten-point scale.¹⁷⁹

Accessing hospice care early can increase a patient's quality of life near the end of life for a variety of reasons. One example presents itself in the place where most hospice patients die. Most patients, generally speaking, would like to die at home.¹⁸⁰ Most hospice patients die at home, yet if they have been in hospice less than seven days, statistics indicate they are unlikely to access hospice services at home.¹⁸¹

Doctor Wright's evidence also indicates that earlier access to hospice is better for family caregivers.¹⁸² Professor Elizabeth H. Bradley and others support that conclusion with a correlation arising from a study of hospice patients with cancer and their family members, report-

¹⁷⁹ See *id.* at 1668.

¹⁸⁰ See Beckwith II, *supra* note 19, at 49-50 ("Ninety percent of Americans prefer to spend their final days at home surrounded by individuals who mean the most to them."); Judith C. Hays et al., *Preference for Place of Death in a Continuing Care Retirement Community*, 41 GERONTOLOGIST 123, 123 (2001) ("Most patients in the United States would prefer to die at home" (citations omitted)); Siew Tzuh Tang, *When Death Is Imminent: Where Terminally Ill Patients with Cancer Prefer to Die and Why*, 26 CANCER NURSING 245, 249 (2003) (noting nearly ninety percent of terminally ill cancer patients would choose to die at home); Susan W. Tolle et al., *Oregon's Low In-Hospital Death Rates: What Determines Where People Die and Satisfaction with Decisions on Place of Death?*, 130 ANNALS INTERNAL MED. 681, 681 (1999) ("Surveys indicate that most Americans would prefer to die at home or in a homelike setting" (citations omitted)). One must not generalize too broadly. Not all patients want to die at home, as Siew Tzuh Tang has noted. See Tang, *supra* note 180. Moreover, as Catherine Jones has noted, "a peaceful, accepted death, at home with family present" is "a white, middle class death." Catherine J. Jones, *Assistance in Dying: Accounting for Difference*, 19 W. NEW ENG. L. REV. 405, 412 (1997). As with many issues surrounding death and dying, cultural background may influence this desire. Patients of some Asian cultures, for example, may wish to die in an institution. See *id.* ("Those of Chinese descent may not want to die at home because of cultural beliefs that their ghost will haunt the place where they died, and they do not want to impose that on their family." (citation omitted)). For a discussion of cultural differences, although limited to African-American and Hispanic cultures, see Perez & Cerminara, *supra* note 101.

¹⁸¹ Teno et al., *supra* note 86.

¹⁸² See Wright et al., *supra* note 20, at 1670-71.

ing that “[c]aregivers of patients with few days of hospice care were at increased risk of subsequent major depressive disorder”¹⁸³

The effect on caregivers is an important consideration because, as Rhymes noted, family-patient relationships are laden with conflicts, guilt, and strain near the end of life. Hospice provides support for family caregivers¹⁸⁴ that should not wait until too near the end of the patient’s life.¹⁸⁵ This is especially important in a legal system that greatly values patient autonomy, which can result in omitting some family members from the end-of-life decision-making process, causing “immense moral uncertainty” among family members when it is time to make decisions about commencement, continuation, refusal, or withdrawal of treatment.¹⁸⁶

Accessing hospice services earlier may even reduce or eliminate the perceptions of hospice care that sometimes cause patients to hesitate to access it. One such concern is about the quality of hospice care.¹⁸⁷ The results of a nationwide survey on hospice care indicate earlier referral to hospice care enhances bereaved family members’ perceptions of the quality of that hospice care when thinking back on the experience after the deaths of their loved ones.¹⁸⁸ In other words, bereaved families thought more highly of the quality of hospice care the longer their de-

¹⁸³ Elizabeth H. Bradley et al., *Depression Among Surviving Caregivers: Does Length of Hospice Enrollment Matter?*, 161 AM. J. PSYCHIATRY 2257, 2259 (2004) (finding that 24.1% of caregivers of patients spending three or fewer days in hospice met diagnostic criteria for major depressive disorder as compared with only nine percent of caregivers of patients with longer hospice enrollment).

¹⁸⁴ See Sharla Wells-DiGregorio, *Family End-of-Life Decision Making*, in DECISION MAKING NEAR THE END OF LIFE: ISSUES, DEVELOPMENTS, AND FUTURE DIRECTIONS, *supra* note 23, at 247, 250 (“Families provide the majority of care to a loved one when the loved one becomes ill.”); *see also id.* (describing the many roles a family caregiver assumes).

¹⁸⁵ See Morrison, *supra* note 23, at S-81 (noting that “the needs of patients *and families* are not met solely by physician office visits and acute care hospitals”) (emphasis added).

¹⁸⁶ Wells-DiGregorio, *supra* note 184, at 247-48 (finding that “many families live with persistent doubts and regrets regarding [end-of-life] decisions made for loved ones in the absence of shared advance care plans” (citation omitted)); *see id.* at 247-48 (arguing for family-based advance care planning).

¹⁸⁷ *See supra* text accompanying note 100.

¹⁸⁸ Teno et al., *supra* note 86, at 122.

ceased family members received hospice services. To the extent that concerns about quality of care can impede access, positive views of hospice care resulting from previous patients' longer lengths of stay could prompt a broader subset of later patients to access hospice services earlier.

Relating the process of accessing hospice back to Kübler-Ross's work also assists in analyzing the issue. Accessing hospice before reaching the acceptance stage of the dying process is consistent with the view of hospice as comforting and easing the path to death. For example, palliation of physical pain is useful as early as possible¹⁸⁹ and even produces physical benefits of its own.¹⁹⁰ To the extent that hospice providers treat pain more completely than other providers, as indeed they are specifically trained to do, accessing hospice services earlier in the process of dying will permit better, earlier relief of physical pain for patients.

Moreover, accessing hospice before acceptance is consistent with the view of hospice as easing mental pain in the form of depression.¹⁹¹ Hospice services can be quite useful in helping patients and families with the depression they experience before the patients arrive at acceptance.¹⁹² In fact, the various mental health counseling services available through hospice could also be useful in counseling patients and families through the anger and bargaining stages—patients and families may benefit by accessing hospice services any time after the stage at which they are still experiencing denial and isolation. The holistic treatment of both mind and body that hospice provides would help promote peace of mind and relaxation, permitting the dying process to be as humane as possible if patients access hospice as early as possible.

¹⁸⁹ Hales et al., *supra* note 108, at 913 (finding relief from physical pain and suffering the most important aspect of a good death across studies); *see also* World Health Organization, *supra* note 18 (stating the WHO definition of *palliative care*).

¹⁹⁰ *See supra* text accompanying notes 83-85.

¹⁹¹ Hospice is intended to relieve both physical and mental pain. Hales et al., *supra* note 108, at 913 (noting “it is both a conceptual and measurement question whether distinctions can be made among suffering in the physical, psychological, and spiritual or existential domains”).

¹⁹² *See* Wright et al., *supra* note 20, at 1666 (stating that hospice leads to less major depressive disorders among bereaved caregivers).

B. Possibilities for Eliminating the Dichotomy

Sociological, psychological, and medical research thus demonstrates the conceptualization of hospice as a place “you go to die”¹⁹³ is inaccurate, both in its description of hospice as a place and in its cramped view of hospice services’ benefits. Hospice care encompasses a much more inclusive set of services than such a characterization indicates. Congress should recognize this fact, revising the funding limitations that reinforce this view of hospice within the Medicare system. Doing so will not eliminate the conundrum of determining when enough is enough¹⁹⁴ with respect to curative treatment for any given patient.¹⁹⁵ Nor will it resolve culture clashes between patients, families, and physicians who believe in doing everything to stave off death and those who view death as a natural, if final, stage of life.¹⁹⁶ Doing so, however, could eliminate confusion and provide a more comfortable space within which to carefully and thoughtfully work through such conundrums and conflicts. Following are some suggestions for improvement focusing on blurring or eliminating the sharp line the law attempts to draw between curative and palliative treatment.

One option policy makers should consider is providing Medicare funding of hospice-like services even before patients become eligible for hospice services due to terminal diagnoses. The law could authorize payment for pastoral care, counseling services, and more social work even before a patient qualifies for the hospice benefit. This sort of

¹⁹³ FINS, *supra* note 16, at 135.

¹⁹⁴ See generally Harrington & Smith, *supra* note 95.

¹⁹⁵ Whether a patient has experienced a *good* death, and what the patient believes a *good* death would be are inherently subjective constructs, quite likely to result in varying decisions about when and under what circumstances to halt curative treatment. See Hales et al., *supra* note 108, at 912-13.

¹⁹⁶ Compare NULAND, *supra* note 104, at 257-58 (describing how a fear of failure and possibly death causes some physicians to continue treatment, but then abandon the patient when recovery is no longer possible) *with id.* at 267 (“A realistic expectation also demands our acceptance that one’s allotted time on earth must be limited to an allowance consistent with the continuity of the existence of our species.”). See also Ahmed Elsayem et al., *Palliative Care Inpatient Service in a Comprehensive Cancer Center: Clinical and Financial Outcomes*, 22 J. CLINICAL ONCOLOGY 2008, 2012 (2004) (describing nurses on both side of the divide).

“bridge-to-hospice program”¹⁹⁷ could provide patients, families, friends, and caregivers with access to some of the holistic services provided by hospice care even before the Medicare hospice benefit kicks in.¹⁹⁸

Studies of cancer patients seem to support the efficacy of such in-between programs. Even as cancer is the single most prevalent terminal diagnosis for patients receiving hospice care,¹⁹⁹ many cancer patients must wait to obtain hospice care until after they complete multiple rounds of chemotherapy.²⁰⁰ Because many clinicians believe that “[s]ymptom management and psychosocial support for patients with advanced cancer and their families must be a part of the continuum of care, not just once life-prolonging therapies fail[,]”²⁰¹ there are a handful of studies examining integrated palliative care,²⁰² simultaneous care,²⁰³ inpatient palliative care services,²⁰⁴ and integration of palliative care into routine cancer care.²⁰⁵ Some researchers reported positive re-

¹⁹⁷ See Wright & Katz, *supra* note 87, at 326; see also Stephen R. Connor, *Development of Hospice and Palliative Care in the United States*, 56 OMEGA 89, 96 (2007) (advocating “an expansion of hospice benefits to include reimbursement for interdisciplinary consults at an earlier stage of the illness and for care management services prior to admission to a formal hospice”).

¹⁹⁸ See generally David Casarett & Janet L. Abraham, *Patients With Cancer Referred to Hospice Versus a Bridge Program: Patient Characteristics, Needs for Care, and Survival*, 19 J. CLINICAL ONCOLOGY 2057 (2001); Susan C. Miller et al., *The Medicare Hospice Benefit’s Influence on Dying in Nursing Homes*, 1 J. PALLIATIVE MED. 367 (1998) (discussing how offering Medicare hospice benefits to nursing home residents may improve their quality of care).

¹⁹⁹ See NHPCO Facts, *supra* note 41, at 7-8 (finding the primary diagnosis of 41.3% of hospice patients in 2007 was cancer).

²⁰⁰ See Jennifer S. Temel et al., *Phase II Study: Integrated Palliative Care in Newly Diagnosed Advanced Non-Small-Cell Lung Cancer Patients*, 25 J. CLINICAL ONCOLOGY 2377, 2377 (2007) (“[P]atients receiving chemotherapy are not eligible for hospice care, leaving many patients and families struggling without the specialized symptom management and support available through hospice and palliative care programs.”).

²⁰¹ *Id.* at 2378.

²⁰² See, e.g., *id.*

²⁰³ See, e.g., Frederick J. Meyers et al., *Simultaneous Care: A Model Approach to the Perceived Conflict Between Investigational Therapy and Palliative Care*, 28 J. PAIN & SYMPTOM MGMT. 548 (2004).

²⁰⁴ See, e.g., Elsayem et al., *supra* note 196.

²⁰⁵ See, e.g., Marie Bakitas et al., *Project ENABLE: A Palliative Care Demonstration Project for Advanced Cancer Patients in Three Settings*, 7 J. PALLIATIVE MED. 363,

sults such as better understanding of the psychosocial impact of disease on patients²⁰⁶ and increased access to hospice and palliative care services,²⁰⁷ while other studies demonstrated that such programs are financially viable, causing them to recommend further research about the possible benefits of such programs.²⁰⁸ Such results among advanced cancer patients indicate that policy makers should explore the idea of funding such integrative or bridge programs for non-cancer patients in the same situation.

As an across-the-board shift in policy, medical professionals additionally suggest that patients should not have to renounce curative treatment before payors will fund hospice services.²⁰⁹ Some lawmakers

369 (2004); Randall Krakauer et al., *Opportunities to Improve the Quality of Care for Advanced Illness*, 28 HEALTH AFF. 1357 (2009); T.J. Greaney, *A Gentle Death: Program Provides Patients With Comfort and Control*, COLUMBIA DAILY TRIBUNE, June 21, 2009 (describing *comfort pathways* available to patients through the Missouri Palliative Care Program in the University of Missouri Health Care System); *Project Safe Conduct Integrates Palliative Goals into Comprehensive Cancer Care: An Interview With Elizabeth Ford Pitorak, MSN, APRN, CHPN, and Meri Armour, MSN, RN*, INNOVATIONS IN END-OF-LIFE CARE, <http://www2.edc.org/lastacts/archives/archivesjuly02/featureinn.asp> (last visited April 12, 2010).

²⁰⁶ See Meyers et al., *supra* note 203, at 555.

²⁰⁷ See Bakitas et al., *supra* note 205, at 371 (finding a substantial increase in patient referrals at the sites testing this palliative model of care).

²⁰⁸ See Elsayem et al., *supra* note 196, at 2013.

²⁰⁹ See Wright & Katz, *supra* note 87, at 326. One physician describes the hospice benefit as “so restrictive” because “it requires divorcing yourself from your patient’s care because you can’t be their cancer doctor anymore.” *Id.*; MATHERLEE, *supra* note 9, at 3 (describing press release about clinical trials of patients receiving both investigational chemotherapy and palliative care) (citing Press Release, UC Davis Health System, *Cancer Patients Enrolled in Clinical Trials do Better When They Receive Palliative Care: Researchers Argue Quality-of-Life Issues Need More Attention in Clinical Trials* (May 21, 2002), http://www.ucdmc.ucdavis.edu/news/palliative_care.html); see also Teno et al., *supra* note 86, at 125 (noting that despite the disparity in the amount of time experts believe patients should spend in hospice and the amount of time most patients actually spend in hospice, most families studied say that their deceased family member who had been referred to hospice spent the right amount of time in hospice care). These statistics raise the issue of why patients’ families apparently believe the amount of time their loved one spent in hospice was appropriate even though it was less than the experts believe is necessary for maximum benefit. Teno states that “[t]he striking variation in the perception of being referred ‘too late’ calls for research to understand whether hospices are using different organizational interventions to improve access to hospice services. For example,

agree—the proposed Advance Planning and Compassionate Care Act of 2009 included a number of revisions to federal law relating to advance care planning and other end-of-life issues.²¹⁰ For example, section 226 of the Act would have expanded Medicare coverage for hospice beneficiaries eighteen years of age or younger to include curative care.²¹¹ Additionally, in 2007 Senator Ron Wyden (D-OR.) suggested amending the Medicare statute and regulations to eliminate the requirement patients forego curative treatment in order to receive payment for hospice services.²¹² Moreover, in 2000 Vermont legislators passed a statute calling for a study about “the feasibility of allowing Vermonters to receive services under the state’s Choices for Care program while also receiving hospice benefits under Medicaid or Medicare.”²¹³

Demonstration projects or other studies concerning the reforms already underway would help define the contours of such legislative proposals in the future. As long ago as 2003, the Hastings Center and

many hospices are now adopting ‘open access’ policies to allow dying patients to receive potentially ‘life-prolonging treatment.’ This intervention potentially could improve access to hospice services, reducing bereaved family members’ perceptions that their dying relatives or friends were referred ‘too late’ to hospice services. Future research is needed to characterize this variation by hospice program in regard to whether there are different processes of care, consumer education efforts, and/or different hospice policies that lead to improved perceptions of the quality of care.” Teno et al., *supra* note 86, at 124-25; *see also* Reed Abelson, *A Chance to Pick Hospice, and Still Hope to Live*, N.Y. TIMES, Feb. 10, 2007, at A1, *available at* 2007 WLNR 2644448 (describing programs termed *open access* hospice).

²¹⁰ *See* Advance Planning and Compassionate Care Act of 2009, S. 1150, 111th Cong. (2009).

²¹¹ *Id.* at § 226. This section would have added a sentence to the statutory provision requiring Medicare beneficiaries waive certain benefits, providing that persons eighteen years of age or younger need not waive those benefits. *Id.*

²¹² Healthy Americans Act, S. 334, 110th Cong. § 452 (2007). *But see* Patient Protection and Affordable Care Act, H.R. 3590, 111th Cong. § 3140(a) (2010) (establishing, as part of health care reform, a demonstration program “under which Medicare beneficiaries are furnished, during the same period, hospice care and any other items or services covered under [Medicare]”).

²¹³ H. 435, § 17, 2009 Gen. Assem., Reg. Sess. (Vt. 2009), *available at* <http://www.leg.state.vt.us/docs/2010/bills/House/H-435.pdf> (enacted May 18, 2009). Vermont’s Choices for Care program is a Medicaid-funded program supporting access to long-term care for older patients and patients with disabilities. *See* Choices for Care (1115 Long-Term Care Medicaid Waiver)—Division of Disability and Aging Services, <http://www.ddas.vermont.gov/ddas-programs/programs-cfc> (last visited April 12, 2010).

the National Hospice Work Group recommended “that Congress approve a series of demonstration projects to Advance Hospice Access (AHA)[,]” with a goal of “advanc[ing] hospice access for persons who do not yet qualify for traditional hospice due to extended or uncertain prognosis and/or their preference for therapies directed toward cure or prolongation of life.”²¹⁴ Since that time, the coalescence of medical professionals and lawmakers recognizing the benefits of such programs may have resulted in proposals with some traction in the public policy arena. As Doctor Camilla Zimmermann and Doctor Richard Wennberg argue, “The hospice and palliative care movements were built on dichotomies that resonated with the public at the time they were constructed and helped to make the public and policy makers aware of the unique needs of the terminally ill.”²¹⁵ Yet, “[t]he dichotomy of comfort and cure and the idea that palliative care represents comfort when cure is no longer possible is based on an illusion of the curability of most of our medical diseases, for many of which a cure is not available from the time of diagnosis.”²¹⁶ As a subset within the larger field of palliative care, hospice services should not be regulated to the *comfort* side of the false dichotomy between comfort and cure. The idea of eliminating the legal distinction for purposes of Medicare reimbursement is worth exploring.

V. CONCLUDING THOUGHTS

The existing framework requires dying patients to accept the inevitability of approaching death before most payors will fund hospice services. Such a state of affairs is far from ideal because hospice services provide both physical and psychological benefits long before patients accept their fates. It is time for policy makers to blur the existing line between what Medicare will pay for (palliative treatment) and what it will not pay for (curative treatment) if a patient chooses to access hospice services near the end of life. Doing so will pave the way for other payors to do so as well, given that many payors mimic Medicare in their funding rules.²¹⁷

²¹⁴ Jennings et al., *supra* note 87, at S53.

²¹⁵ Camilla Zimmermann & Richard Wennberg, *Integrating Palliative Care: A Postmodern Perspective*, 23 AM. J. HOSPICE & PALLIATIVE MED. 255, 257 (2006).

²¹⁶ *Id.*

²¹⁷ See *supra* notes 10-11 and accompanying text.

One issue that arises when considering such action is whether accessing curative treatment at the same time as preparing for death is consistent with hospice philosophy. Administering both curative and palliative care could create a clash of cultures between a patient's hospice caregivers and curative treatment providers, resulting in a net decrease in quality of care. Yet, Samira Beckwith says one myth of hospice is that "[h]ospice is mostly about dying and giving up hope."²¹⁸ She states in correction:

The opposite is true. Hospice is about making the most of life each day.

. . . Outlooks change, roles switch and priorities shift when people realize that their time is limited. Hospice professionals help patients and families sort through all of these challenges.

They can also help families understand the complex health care system and ensure that all available community resources are provided.²¹⁹

Similarly, some studies recognize that it is possible to inspire hope even when fully explaining poor prognoses.²²⁰ Rather than clashing, which negatively affects quality, it may be possible for the two cultures to work in harmony. Any cultural issue should not stand in the way of research aimed at a solution.

Furthermore, permitting patients to access hospice services while still undergoing at least some curative treatment could assist with patients' continuity of care. This is important because some patients reported feeling abandoned when they began to access hospice services.²²¹ Such abandonment (or the impression of abandonment) may

²¹⁸ Beckwith I, *supra* note 5, at 57.

²¹⁹ *Id.*

²²⁰ See Mack et al., *supra* note 105, at 5639 (discussing the results of a study conducted at the Dana-Farber Cancer Institute and Children's Hospital in Boston that studied the relationship between prognostic disclosure by doctors and possible outcomes such as hope, trust, and emotional distress on their patients).

²²¹ See Christopher K. Daugherty & David P. Steensma, *Overcoming Obstacles to Hospice Care: An Ethical Examination of Inertia and Inaction*, 20 J. CLINICAL

partially result from the discontinuity of care that results under current law. Under the current system of payment for hospice services, patients who are ambivalent about the decision to forego curative treatment may change their minds, but must renounce hospice services before Medicare will again fund curative care.²²² To the extent that a patient does this, blurring or eliminating the false dichotomy between the two should provide better continuity of care. The patient would not experience frustrations associated with starting, then stopping, and possibly re-starting hospice services while deciding whether to continue curative treatment. Currently, to avoid such disruptions in continuity of care, the practice is for the patient to wait until he or she is certain about ceasing curative treatments before beginning hospice care. Without that hindrance, some patients may access hospice care at a time when they and their families can take better advantage of it.

Such a change in the funding for hospice care thus could institutionalize the legal and moral imperative to honor a patient's change of heart that surfaces in other areas of end-of-life law. For example, courts and surrogate decision makers determine whether the wishes expressed in a patient's advance directive reflect current—rather than past—wishes,²²³ because one concern about advance directives is that they

ONCOLOGY 2752, 2753-54 (2003). This is a concern for physicians as well. "Many physicians value their relationships with patients and fear that referral to hospice will end their involvement with [the patients], although this is not the usual reality." Jennings et al., *supra* note 87, at S37.

²²² See Thompson et al., *supra* note 125, at 465-66. The move from hospice care to curative care and back does not necessarily result in receiving care from new physicians. The hospice plan of care results from collaboration with the patient's attending physician. See 42 C.F.R. § 418.56(b) (2009); MEDICARE HANDBOOK, *supra* note 80, at 5-11 to 5-12 (explaining that hospice personnel "in conjunction with the patient's attending physician are responsible for the palliation and management of the terminal illness and conditions related to the terminal illness"); see also Beckwith III, *supra* note 35, at 53 (noting that the patient's physician "works with the hospice team in everyday matters"). Hospice personnel are uniquely tasked with "both provid[ing] and oversee[ing] palliative care as the patient moves across care sites with which they have contractual relationships." True Ryndes & Linda Emanuel, *Is Discontinuity in Palliative Care a Culpable Act of Omission?*, in *Access to Hospice Care: Expanding Boundaries, Overcoming Barriers*, *supra* note 87, at S45, S45.

²²³ See, e.g., *In re Guardianship of Browning*, 568 So. 2d 4, 13 (Fla. 1990) (finding a patient's past expressions are valid indications of present intentions because patient did not revise her previously stated wishes, thus "even the failure to act constitutes a

may not reflect changes of heart.²²⁴ Similarly, both Oregon and Washington have laws regulating physician aid in dying that specifically account for, and guard against, patients and providers unduly discounting the ambivalence of a patient's desire for lethal-strength prescriptions.²²⁵ Thus, honoring a patient's change of heart regarding access to curative treatment without forcing the patient to forego hospice services that have already begun would be consistent with existing policies in other areas concerning end-of-life planning.

In this vein, it is worth noting that making it possible to access hospice services even while pursuing curative treatment does not *oblige* a patient to access hospice services or to continue curative treatment. Consistent with the general right to refuse treatment, terminally ill patients would retain the ability to refuse either hospice services or curative treatment if they so choose. There is, however, an important difference between *requiring* patients to forego curative treatment in order to have hospice services funded and having hospice services regardless of whether the patient continues curative treatment. The not-uncommon factual situation of a dying patient who tests positive for the human immunodeficiency virus (HIV) illustrates the difference associated with the all-important concept of control.

An HIV-positive patient whose condition has progressed to full-blown acquired immune deficiency syndrome (AIDS) still does not always die from AIDS itself.²²⁶ By definition, AIDS makes the patient vulnerable to other conditions, so the virus may not kill the patient,

choice"); *In re Westchester County Med. Ctr.*, 531 N.E.2d 607, 616 (N.Y. 1988) (Hancock, J., concurring) (describing the requirement for a "clear expression of a present intention to forego" the treatment in question) (emphasis added).

²²⁴ See Rebecca Dresser, *Precommitment: A Misguided Strategy for Securing Death With Dignity*, 81 TEX. L. REV. 1823, 1834-35 (2003); Richard S. Markovits, *Precommitment Analysis and Societal Moral Identity*, 81 TEX. L. REV. 1877, 1903 (2003).

²²⁵ Patients requesting assistance in dying must make one written and two oral requests, with the oral requests taking place at least fifteen days apart from each other. See OR. REV. STAT. § 127.840 (2009); WASH. REV. CODE § 70.245.090 (2009). The patients may rescind their requests at any time. See OR. REV. STAT. § 127.845; WASH. REV. CODE § 70.245.100.

²²⁶ See Cascade Collaboration, *Effective Therapy Has Altered the Spectrum of Cause-Specific Mortality Following HIV Seroconversion*, 20 AIDS 741, 743-44 (2006).

rather opportunistic infections or other diseases such as hepatitis or cancers developing from the immunodeficiency may be the direct cause of death.²²⁷ Consider an AIDS patient that qualifies for Medicare and while in hospice care develops a staph infection. This patient could undergo curative treatment for the infection at Medicare's expense while Medicare also pays for hospice care. However, the patient could refuse curative treatment for the staph infection because of the patient's basic right of self-determination. Alternatively, another AIDS patient, also qualifying for Medicare but terminally ill due to a cancer that developed because of the immunodeficiency, must forego curative treatment for the cancer before Medicare will fund hospice services.

Implementing a system that blurs or eliminates the supposed line between curative and palliative care would put both types of patients on the same footing. It would be the patient's choice whether to refuse or accept curative treatment for the cancer, and whether to refuse or accept hospice services, without a negative linkage between the two. The control is entirely in the patient's hands under the latter funding system, whereas the current funding system limits patient control.²²⁸

Proposals to increase Medicare coverage doubtless raise eyebrows in light of Congress's focus on cost cutting when enacting the Medicare hospice benefit rules.²²⁹ On the surface, blurring or eliminating the line between palliative and curative treatment would seem to increase financial costs to the Medicare system, as well as to other payors.²³⁰ If a patient accesses hospice care earlier than he or she would have otherwise, the increased time in hospice care will naturally in-

²²⁷ *Id.*

²²⁸ See 42 C.F.R. § 418.24(d)(2) (2009). To be more precise, the patient's choice whether to undergo treatment in the case of the staph infection does not bring with it financial considerations; Medicare will fund both that medical treatment and the holistic, supportive hospice treatment. However, the patient's choice whether to undergo treatment in the case of the cancer brings with it major financial considerations. If the patient wants the cancer treated, the patient must forego payment for hospice services, and vice versa. In this circumstance, the patient still has a choice, but it is a choice made under economic duress.

²²⁹ See *supra* Part III.B.

²³⁰ See Wright & Katz, *supra* note 87 (noting that "some observers worry that nationwide open access could bankrupt Medicare").

crease the cost of hospice care.²³¹ In addition, accessing even some curative treatment at the same time as receiving hospice benefits would multiply costs—considering the money spent on both hospice care and intensive end-of-life care.²³²

Closer examination, however, indicates that neither of these two seemingly straightforward propositions necessarily leads to the conclusion that proposals to expand Medicare coverage are dead in the water. First, while financial costs are important, studies could demonstrate that hospice's intangible benefits are so valuable policy makers should value those benefits at least equally with tangible considerations.²³³ Second, despite the accuracy of the above statements, studies might reveal that costs do not increase, or do not increase as much as expected, with the change in Medicare coverage. Hospice care costs less than curative care,²³⁴ so paying for more hospice care plus some curative care still may not cost as much as intensive end-of-life care.²³⁵ Moreover, hos-

²³¹ MEDPAC, *supra* note 49, at 210. With a per diem structure, longer stays are more expensive, by definition. *See id.* at 204. “Beyond [twenty-one] days, the magnitude of deficits declined, and the stays became profitable.” *Id.* at 219.

²³² *See id.* at 232-33 (noting that when forgoing curative treatment, patient's avoid expensive medical costs at the end of their life); Abou-Sayf et al., *supra* note 11, at 84 (characterizing a National Hospice study as finding cost savings in home hospice care over hospital stays, and a Kaiser Permanente study as indicating that hospice saved costs because hospice care was a substitute for inpatient stays).

²³³ *See* Wardwell, *supra* note 57, at 502-03; Sulmasy, *supra* note 14 (making the case for coverage of hospice care as part of “health care justice”); *see also* Patient Protection and Affordable Care Act, H.R. 3590, 111th Cong. § 3140(b)(1) (2010) (requiring, as part of health care reform, “an independent evaluation” of three-year concurrent care demonstration program to “determine whether the demonstration program has improved patient care, quality of life, and cost-effectiveness for Medicare beneficiaries participating in the demonstration program”).

²³⁴ Ezekiel Emanuel & Linda L. Emanuel, *The Economics of Dying—The Illusion of Cost Savings at the End of Life*, 330 NEW ENG. J. MED. 540-44 (1994) (describing a series of studies “estimat[ing] that in the last month of life, home hospice care saves between 31 and 64 percent of medical care costs[,]” although also noting the studies may have overstated these cost savings (citations omitted)); *see also* MEDPAC, *supra* note 49, at 209 (acknowledging the reduced cost is due to decreased use of Part A Medicare services in the last few months of life).

²³⁵ *See* MEDPAC, *supra* note 49, at 209 (noting hospice use will result in lower Medicare spending with patients that require inpatient care at the end of life, such as cancer, as opposed to patients that do not normally incur a lot of inpatient care, such as those with Alzheimer's disease).

pace lengths of stay are already increasing, despite the lack of coverage for curative care.²³⁶ Thus, an amendment to the law that allows people to access both curative treatment and hospice services would not be solely responsible for increased hospice lengths of stay.

Finally, permitting people to elect hospice services while accessing at least some curative treatment could allow them to reach acceptance earlier than they would have without hospice, thus lessening the total amount of time spent accessing curative treatments.²³⁷ Perhaps, as indicated by analogy to procedural justice literature, patients facing death will be more at peace with the result if they are able to have more control over their treatment and care.²³⁸ Patients with terminal diagnoses may reach the acceptance stage more quickly if they can continue at least some curative treatment while beginning to receive some of the psychological and physical benefits of hospice care. If patients are able to keep pursuing at least some curative treatments, then perhaps they will be more likely to accept mortality without fighting until the last possible minute.²³⁹ If this is the case, then perhaps patients will spend less overall effort on curative treatments if they have access to some curative treatment at the beginning of their hospice care experiences. Thus, in addition to spending less it is likely that each patient would experience a higher quality of life during his or her remaining days²⁴⁰ due to the higher-value care received.²⁴¹

²³⁶ See *id.* at 210 (“[T]he number of long hospice episodes is increasing.”); *id.* at 207 (“Average length of enrollment in hospice has been increasing since the coverage period was expanded in 1997.” (citation omitted)). But see MEDICARE TRENDS, *supra* note 110, at 2 (“Since 2006, the average [length of stay] has begun to decline slightly, dropping [from seventy-three days] to [seventy-one] days in 2008, which is a 48% increase from 1998.”).

²³⁷ See MEDPAC, *supra* note 49, at 210 (discussing the increasing trend of longer lengths of hospice stays). But see *id.* at 233 (suggesting that hospices may seek out patients who are more likely to have lengthy hospice stays because these patients are more profitable).

²³⁸ See *supra* note 162 and accompanying text.

²³⁹ Compare Meyers et al., *supra* note 203, at 553 tbl.2 (indicating a longer length of hospice stay with simultaneous care than with usual care), with Bakitas et al., *supra* note 205, at 371 (indicating one measure of success was increased hospice referrals and thus increased access to care).

²⁴⁰ See *supra* notes 80-82, 179 and accompanying text.

²⁴¹ See Baicker, *supra* note 13, at 678.