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The Value of Your Last Day: The Information Asymmetry in End-of-Life Care Planning Is Levying a High Human Cost in America

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I. Introduction

Medical science is having an Icarus moment. Dead set on conquering a war on disease, humans have worked themselves into a paradox: people are living for longer but with greater suffering. The result is a lower quality of death, which flows from one's quality of life at the end of life. This is not "diminishing returns" but rather damaging returns. We strive to avoid the inevitable at the cost of comfort later in life. The hypothetical "would you rather two good months or twelve bad months" is increasingly being met with the answer of "twelve bad months." The state of many terminal patients is unsettling; some are full of drugs and protruding tubes, while others are kept alive in the latest stages of disease only by ventilators, but nearly all are trapped in their hospital beds.¹ Often, these patients are in these states as the result of loved ones who are not ready to say one final goodbye – and understandably so.² Death is the most terrifying existential reality humans all face. However, in our pursuit for just a little more time, the resulting human cost is more pain, more suffering, less freedom, and, ultimately, less enjoyment of those invaluable final moments of life.

Aside from the physical suffering and mental anguish associated with superficially extended life, this manner of living is often inconsistent with patients' wishes. While intuitively we believe everyone would like to live as long as possible, that common sense belief is a misconception; a substantial segment of the population has fairly firm lines when it comes to quality of life.

The issue is further made confusing when considering some minority groups prefer therapeutic treatment – or treatment of the disease – rather than symptom-focused treatment. The divergence from the general preference for end-of-life care stems from historic socioeconomic

¹ ATUL GAWANDE, BEING MORTAL 154 (2014).

² *Id.*

factors that ultimately result in poorer quality of treatment. This ineffective treatment arises where patients are poorly informed and poorly treated. These minority communities provide insight as to some of the broader structural problems in American end-of-life care but also provide grounds to discuss other realities of advisement in end-of-life care.

Without a doubt, seeking to fight disease and save lives is a noble motivation. However, this motivation has resulted in more suffering on average at the end of life. But what precisely causes our modern death-avoidance drive? Is it cultural? Is it innate in humans? Is it motivated by some gluttonous healthcare companies, preferring a slow and profitable bloodletting instead of a sooner and more natural conclusion to life? Or is it as simple as inadequate information sharing, poor planning, and ineffective guiding of patients at the end of life? While there may be reason to suspect Medicare's fee-for-service structure, which effectively incentivizes overtreatment of the very-ill,³ is to blame here, I believe the issue is inadequacy in American planning. If such an incentive does in fact exist, inadequate planning and information sharing certainly helps continue the con; but remedying the information asymmetry in healthcare may counter the con.

Most patients are not trained in medicine; even among those that are, the patients may not be trained in a specific disease field or in palliative care, leaving them nearly as uninformed as a layperson. At the same time, patients and their families feel helpless when faced with potential death. While we try to reassure ourselves that, after death, all will be well, there is still an understandable fear of the great unknown. Lacking medical expertise and facing a daunting decision, a patient will likely defer to the judgment of his or her treating physician.

³ See Isaac D. Buck, *Breaking the Fever: A New Construct for Regulating Overtreatment*, 48 U. OF CAL., DAVIS LAW REVIEW 1261, 1265-66 (2015). The article notes a culture of overtreatment and overspending in the United States and suggests that the system of reimbursement encourages this culture. There are no empirical studies concluding causation, but the evidence certainly suggests a correlation.

The physician, meanwhile, will often seek to avoid a fatal outcome. The reasons are twofold: a professional toll and a human toll. In the professional culture of medicine, death is regarded as the worst medical outcome. Whether consciously or subconsciously, physicians fear that death of a patient reflects poorly on the medical staff and the medical institution. Providing further professional motivation in pursuing the preservation of life at all costs is cost itself: hospitals and physician groups are paid on a fee-for-service basis under Medicare Part B. Of course, there is also the human toll death takes on individuals, especially in a situation where one could have saved another – which is precisely the situation many physicians find themselves in daily. There is no doubt that physicians may feel responsible for a patient’s death, and systemic and professional pressures do not relieve those feelings of helplessness and guilt.

These circumstances – medical ignorance on the part of patients and multivariable concerns on the part of physicians – have contributed to our current end-of-life environment where patients are experiencing a lagging quality of death.

Simultaneously, there is an ineffective framework in place to address the issues that our circumstances have wrought. The present regime under Medicare has not been updated significantly in this area since it was amended to include hospice benefits.⁴ Currently, the Medicaid and Medicare statutes offer only barebones end-of-life counseling. Physicians may bill for advanced care planning,⁵ but there is no incentive for physicians to have that extremely difficult conversation.⁶ More importantly, the counseling offered does not come at the crucial

⁴ Muriel R. Gillick, *How Medicare Shapes the Way We Die*, 8 J. HEALTH & BIOMEDICAL L. 27, 29 (2012).

⁵ Advance Care Planning Services, 80 Fed. Reg. 71372 (Nov. 16, 2015). ACP is reimbursed when in the course of an annual wellness visit. The services include “discussion about future care decisions that may need to be made, how the beneficiary can let others know about care preferences, and explanation of advance directives which may involve the completion of standard forms.” *Id.*

⁶ See Birgül Cerit, *Influence of Training on First-Year Nursing Department Students’ Attitudes on Death and Caring for Dying Patients*, 78(4) OMEGA J. OF DEATH AND DYING 342 (2019). While this study concerns nursing students, the article nonetheless reflects upon common human emotions surrounding death that make individuals – medical professionals or not – incredibly uncomfortable with bringing up a patient’s eventual (sometimes nearing) death.

time but rather well before end-of-life care is given; after all, it is *advanced* care planning, not *present* care planning. Moreover, our present billing structure does not offer other helpful services which benefit patients facing death, like how to decide between a “good two months” or a “bad twelve months.” There is no offering for mental health counseling to alleviate the stress of facing death.

Further complicating the issue is the inadequacy of formal medical education in the palliative care arena.⁷ Medical and nursing schools offer little palliative care training outside of the rare palliative care course;⁸ even fewer offer specializations in palliative care.⁹ This results in a notably low pool of palliative care specialists from which hospitals may draw.¹⁰

The underrepresentation of palliative care specialists on medical staffs leaves doctors to administer physical symptom management; this gives doctors the freedom to advise either death-avoiding treatment or death-associated symptom relief. Physicians and nurses are generally unequipped to help end-of-life patients.¹¹ Just as few schools offer palliative care education, few schools offer courses on working with the unique needs of patients daunted by the prospect of death.¹²

The entire medical establishment is unprepared and has not begun to prepare for the complicated needs of a growing elderly and sickly patient population: by 2030, the Baby Boomer

⁷ Head et al., *Improving medical graduates' training in palliative care: advancing education and practice*, ADVANCES IN MEDICAL EDUCATION AND PRACTICE 99, 110 (Feb. 24, 2016).

⁸ Less than one-third of medical schools offer palliative care courses. Robert Horowitz et al., *Palliative care education in US medical schools*, 48 MEDICAL EDUCATION 59, 61 (2014); see also Rebecca Heilweil, *Learning Loss: Nursing students cope with patient death*, THE DAILY PENNSYLVANIAN, Feb. 24, 2016, at 4 (comments by Professor Salimah Meghani, contributor to the 2014 National Institute of Medicine brief).

⁹ Heilweil, *supra* note 8 at 4.

¹⁰ NATIONAL INSTITUTE OF MEDICINE, DYING IN AMERICA: IMPROVING QUALITY AND HONORING PREFERENCES NEAR THE END OF LIFE 3 (2014).

¹¹ Martha E. Billings, M.D., *Determinants of Medical Students' Perceived Preparation To Perform End-of-Life Care, Quality of End-of-Life Care Education, and Attitudes Toward End-of-Life Care*, 13(3) J. OF PALLIATIVE MEDICINE 319 (2010).

¹² Horowitz, *supra* note 8 at 61.

generation will represent 1 in 5 Americans, making projected health care expenditures far exceed \$5 billion yearly, fueled largely by an ever-growing Medicare beneficiary pool.¹³ The government programs are poorly equipped for this problem, the medical profession is poorly educated in this area, and the medical culture is poorly supported in providing patient-centric care.

There has been one enacted bill and two proposed bills that have sought to address some of these issues. In 1990, Congress passed the Patient Self-Determination Act. Then, in 2013, a bipartisan coalition led by Representative Earl Blumenauer of Oregon introduced the Personalize Your Care Act to the House. The Personalize Your Care Act perished in committee, but was reprised in 2015, when another bipartisan coalition led by Senator Mark Warner of Virginia introduced the Care Planning Act to the Senate. While the latter two bills never became law, the duo provide a helpful framework for any bill that seeks to correct the course of this ship. However, the Patient Self-Determination Act has failed to adequately address some problems within our medical system, and the two proposed bills, while helpful, do not quite fully resolve the issues.

I propose amendments to the Medicare statute to effectuate three key changes, following the examples of the Patient Self-Determination Act, the Personalize Your Care Act, and the Care Planning Act. First, nursing and medical schools receiving federal dollars must provide education on end-of-life care to their students, specifically to improve the abilities of all students to communicate with the families and the patients; to better understand the eventuality of death; to change the perception that death should be avoided at all costs; and, importantly, to provide more residency and fellowship positions for palliative care. Second, hospitals receiving

¹³ Andrew Meola, *The aging population in the US is causing problems for our healthcare costs*, BUSINESS INSIDER (July 18, 2019), <https://www.businessinsider.com/aging-population-healthcare>.

Medicare/aid dollars must generally staff more palliative care specialists to ease the family and the patient; as part of this requirement, the palliative care specialists or a multidisciplinary team must offer minor yet appropriate grief counseling to patients and families. Third, establish a professional responsibility standard that compels doctors and nurses to consult and plan with the family and the patient about end-of-life care and understanding what the patient faces ahead; deviation from this standard could give rise to a tort.

This paper will address the issue of poor quality of death in America. Once the scope of the issue is understood, the culture of America that informs how American physicians respond to and address death in the professional setting will be explored. After laying the foundation of the American psyche relating to death, there will be discussion of the psychological literature that will serve as the benchmark for all legal regimes discussed and will inform my analysis. Then, I will analyze the current inadequate legal regime, the proposed Medicare amendments from both the Personalize Your Care Act and the Care Planning Act, and ultimately my own proposed amendments, so far as my proposed amendments go beyond any covered by the two Acts.

II. Obstacles in the Way of Effective End-of-Life Care in America

A. Growing Difficulties in the Hospice Patient Population

The American Cancer Society defines hospice care as

a special kind of care that focuses on the quality of life for people and their caregivers who are experiencing an advanced, life-limiting illness. Hospice care provides compassionate care for people in the last phases of incurable disease so that they may live as fully and comfortably as possible.¹⁴

With its goal of providing comfort to an ailing patient, hospice care seeks to treat the symptoms of disease rather than the disease itself.¹⁵ However, quality hospice care should

¹⁴ THE AMERICAN CANCER SOCIETY, *What is Hospice Care?* (May 10, 2019), <https://www.cancer.org/treatment/end-of-life-care/hospice-care/what-is-hospice-care.html>.

¹⁵ *Id.*

also consider the needs of a patient's family.¹⁶ Most importantly, and oft lost in translation from practitioner to patient, hospice is not giving up – it simply reorients the health care strategy to focus on symptoms of disease when the end of life is expected within six months.¹⁷

Despite the misconception, hospice care still allows for significant life expectancies so patients may make the most of their final days; in 2017, Medicare hospice patients utilized an average of 76 days of hospice care.¹⁸ However, this statistic is somewhat misleading; a little over 25% of such patients used hospice services for over 90 days and a bit over 14% used hospice services for over 180 days.¹⁹ While two and a half months may not sound incredibly long, keep in mind the ultimate goal of hospice care: providing a higher quality of life under hospice's comfort care philosophy than would be provided under curative care.

To qualify for hospice care, a physician must certify a Medicare Part A patient has six months or less to live.²⁰ The further step of admitting the patient poses an additional obstacle to hospice care; a hospice medical director must sign off on admission after considering factors such as the diagnosis of the terminal condition, other health conditions related or not to the terminal condition, and current medically relevant information supporting the diagnosis.²¹ The decision to admit is ultimately left to the attending physician and either the hospice medical director or a physician in the facility's interdisciplinary group, depending on the hospital's

¹⁶ *Id.*

¹⁷ *Id.*

¹⁸ NATIONAL HOSPICE AND PALLIATIVE CARE ORGANIZATION, FACTS AND FIGURES 2018 EDITION 13 (2019).

¹⁹ *Id.*

²⁰ CENTERS FOR MEDICARE & MEDICAID SERVICES, MEDICARE BENEFIT POLICY MANUAL: CHAPTER 9 – COVER OF HOSPICE SERVICES UNDER HOSPITAL INSURANCE 4 (2018).

²¹ *Id.*

internal protocol.²² It may be tempting to conclude that physicians as a professional community should simply join together to certify terminal status in a more libertine manner, but litigation under the False Claims Acts may follow such practices.²³

Medicare provides patients with a “diabolical” choice: elect to receive hospice care alone, or elect to receive life-extending treatment alone – but almost never may a patient choose both.²⁴ Patients’ options are functionally limited to these two choices because reimbursement for hospice is relatively low and facilities prefer more lucrative treatment plans.²⁵ As a result of this dollars-and-cents decision on the part of private medical facilities, medical staff is guided by a standard of care that offers patients a binary choice between two classes of treatment: one that increases the quantity of reimbursement dollars for providers and another that improves the quality of life for patients.

The hospice care population is steadily growing. A study of Medicare Advantage and Medicare Private-Fee-For-Service (or “PFFS”) recipients found 50.4% of PFFS recipients were dying in hospice care in 2015, up from 21.6% in 2009.²⁶ While most adults in America say they would prefer to die at home, only one third of total Medicare recipients die in this setting.²⁷ However, recipients of hospice care are more likely to die at home, with 48.2% of Medicare

²² Social Security Act § 1814(a)(7), 42 U.S.C. § 1395 (2019).

²³ See *United States ex rel. Michaels v. Agape Senior Community Inc. et al.*, 2014 U.S. Dist. LEXIS 41943 (D.S.C. March 28, 2014). There, the U.S. Attorney’s Office for the District of South Carolina pursued litigation under the False Claims Act for falsely certifying Medicare beneficiaries with terminal illnesses had prognoses of six months or less. McDermott Will & Emery, *Oral Arguments Held in Close Watched Agape Case*, FCA UPDATE (Oct. 28, 2016), <https://www.fcaupdate.com/tag/united-states-ex-rel-michaels-v-agape-senior-community-inc/>.

²⁴ Gillick, *supra* note 4 at 30-31.

²⁵ *Id.* Medicare reimburses hospice providers \$151 per day with the expectation that the provider will supply the labor and the medical goods for this daily service fee. *Id.* at 30.

²⁶ Michele G. Sullivan, *Medicare hospital decline, hospice usage increase*, THE HOSPITALIST (June 26, 2018), <https://www.the-hospitalist.org/hospitalist/article/168938/patient-survivor-care/medicare-hospital-deaths-decline-hospice-usage>.

²⁷ Joan M. Teno et al., *Change in End-of-Life Care for Medicare Beneficiaries*, 309(5) JAMA 470-77 (2013).

hospice beneficiaries fulfilling the wish to die at home.²⁸ Hospice recipients in nursing homes are considered the most rapidly growing group in hospice treatment.²⁹

Simultaneously, expenses relating to intensive care unit (or “ICU”) stays have been steadily increasing. The ICU is often a last stop for valiant, though typically futile, efforts to give a patient one last chance at recovery.³⁰ In 2000, for an ICU stay in the last 6 months of life, the national average cost per decedent was \$4,038.56.³¹ In 2005, that number nearly doubled to \$7,977.41.³² By 2010, the average was \$11,453.04 and 2015 saw a record \$13,506.54 spent on average per decedent.³³ In 15 years, the average amount spent on a patient in their last 6 months just in ICUs alone more than tripled. Inflation accounts for only 37.6% of that 334.4% increase.³⁴ Nearly half of Medicare beneficiaries who died of cancer between 2006 and 2011 received potentially aggressive end-of-life care.³⁵ During that time period, there was an increase in utilization of aggressive end-of-life interventions.³⁶

The data suggests that Americans, more than ever, are aggressively treating disease in later stages of life yet not achieving preferred outcomes, particularly by living in settings that most others would not prefer. While the future may be unwritten, one might conclude that, based on trends over the last two decades, this current trend of increased spending and overutilization will only continue. Moreover, if Medicare for All or some other universal healthcare program

²⁸ NATIONAL HOSPICE AND PALLIATIVE CARE ORGANIZATION, *supra* note 18 at 16.

²⁹ Susan C. Miller & Vince N.T. Mor, *The Role of Hospice in the Nursing Home Setting*, 5(2) J. PALLIATIVE MEDICINE 3 (2002).

³⁰ ATUL GAWANDE, *supra* note 1 at 154.

³¹ THE DARTMOUTH INSTITUTE FOR HEALTH POLICY & CLINICAL PRACTICE, ICU CHARGES LAST 6 MONTHS OUTPUT SUMMARY REPORT (PER DECEDENT) FOR YEARS 2000-2015 (on file with author).

³² *Id.*

³³ *Id.*

³⁴ U.S. Inflation Calculator, *Years 2000-2015*, <https://www.usinflationcalculator.com/>.

³⁵ Shi-Yi Wang, et al., *Trends in end-of-life cancer care in the Medicare program*, J. GERIATRIC ONC. 6, March 2016.

³⁶ *Id.* at 2.

becomes the healthcare regime of the United States, we may see this trend drastically increase. Under a universal healthcare model, more people become eligible for hospice and aggressive treatment at earlier points; by effectively removing the need requirements from Medicaid and the age requirements from Medicare, patients have less to lose when pursuing aggressive treatments. Further, improvements in medical science may make certain aggressive treatments more effective and more affordable so that patients who were previously hesitant about these treatments may eventually be more open to these approaches.

The result of the medical community's efforts, while certainly stemming from noble motives, has resulted in a booming demographic of very sick, very aged patients who are opting to pursue treatment much later in life. Notably, these patients are being removed from their homes to receive these often intensive and devastating treatments in the sterile, detached setting of an ICU. The population at issue here is large, growing, and physically limited.

B. The Culture of Death in America

Americans have a bizarre relationship with death. On one hand, death is ubiquitous in our media; at times, it feels as if every generation since the invention of the video camera has dealt with concerns over the commodification of death in television, in music, and in video games. Yet, on the other hand, Americans are intolerant of death. Granted, all living beings have a drive to stay alive, but Americans seem to take death avoidance a step further by trying to outright subvert it. However, this ignores the reality that all living beings may only avoid the Reaper for so long.

Americans love death – not so much the reality of death, but we certainly relish watching death on screen. American media indulges less in portrayals of accurate and commonplace deaths and, instead, very often depicts geysers of blood and gore; violent deaths splash across

our eyes in movies and television; even cable news starting in the Vietnam War era has contributed to Americans' fascination and disgust of death by showing the carnage caused by our many wars abroad. The most common depiction of death in American films is that of a violent death.³⁷ Often, these deaths are met with negative and angry emotions.³⁸ Interestingly, there are similar trends in children's media; in Disney and Pixar films, 47.4% of death scenes produce no reaction amongst the characters.³⁹ Disparate responses to death confuse children and further complicate the American relationship with death.⁴⁰ The natural result is a slow-forged connection in our collective minds that death equals pain and misery.

Further pushing Americans towards life-extension is the nature of humans. People – not just Americans – are particularly desperate when medical issues involving life and death are in question; in fact, feelings of desperation and vulnerability may override a person's rational mind and compel him or her to turn to less promising methods of treatment and, sometimes, outright quackery.⁴¹ Modern mainstream medicine is anything but quackery, yet it still seems to take hold of this same desperation.

The culture of the medical community does not ease this anxiety around death. Rather, that culture has been characterized in one study as viewing death as a failure stemming from a point at which physicians cannot do anymore.⁴² Medical schools push students – our future medical professionals – towards cures, acute care, and high technology.⁴³ The so-called “hidden

³⁷ Schultz & Huet, *Sensational! Violent! Popular! Death in American Movies*, 42(2) OMEGA J. OF DEATH AND DYING 137.

³⁸ *Id.*

³⁹ Tenzek & Nickels, *End-of-Life in Disney and Pixar Films*, 80(1) OMEGA J. OF DEATH AND DYING 49, 58.

⁴⁰ *Id.*

⁴¹ *Mark Richards Pt.11*, KNOWLEDGE FIGHT (Oct. 29, 2019) (downloaded using Apple Podcasts).

⁴² Amy Sullivan et al., *The Status of Medical Education in End-of-Life Care*, 18 J. GENERAL INTERNAL MEDICINE 685, 693 (2003).

⁴³ *Id.*

curriculum,” which is that which is not taught or emphasized in the educational setting, actually works to undermine end-of-life care education.⁴⁴

This cocktail of circumstances resulted in a cultural shift that is more tolerant of life-extending treatments – even if it means more suffering – stemming from a fear that death is more painful than continued treatment, no matter how debilitating and taxing on the patient’s body and mind.⁴⁵ Exemplifying the American obsession with death-avoidance is the uniquely American phenomenon of the “war on disease.”⁴⁶ The spoils of this war on disease are marginal improvements in life expectancy in defiance of the biological reality and eventuality of death.⁴⁷ While the goal of all nations in their medical research should be improving outcomes for patients, the American approach has contributed to a professional culture that tethers a physician’s success to his or her ability to play matador with death.⁴⁸ The fatality rate of a practitioner or facility takes priority over the desires and overall wellbeing of a patient.

The American collective psyche has made it incredibly difficult to discuss the eventuality of death and when it might be appropriate to accept that eventuality. However, the use of Disney’s *The Lion King* and its metaphor of the Circle of Life has been noted as a possible template for discussions around this difficult topic.⁴⁹

C. Racial Disparities in End-of-Life Care

Black and Hispanic Americans represent an interesting yet troubling conundrum in the expansion of advance care planning. These two groups underutilize ACP when compared to white Americans; moreover, the groups underutilize hospice care. Centuries of racial inequality

⁴⁴ *Id.* at 693.

⁴⁵ RICHARD E. MERRITT, STATE INITIATIVES IN END-OF-LIFE CARE 11 (1998).

⁴⁶ Kashyap Patel & Mary Kruczynski, *Palliative and End-of-Life Care*, AMERICAN J. OF MANAGED CARE 2 (2015).

⁴⁷ *Id.*

⁴⁸ *Id.* at 3.

⁴⁹ Tenzek & Nickels, *supra* note 39, at 60.

has had a lingering effect on these groups beyond the widely-acknowledged significant socioeconomic inequality among the races. In addition, cultural differences contribute to the underutilization of these resources.

Black and Hispanic Americans are markedly less likely to utilize existing advance care planning resources. In one survey of Americans forty years of age or older, 8% of black Americans and 18% of Hispanic Americans reported having completed ACP; in stark contrast are the 33% of white Americans who reported having completed ACP.⁵⁰ Hispanic Americans were 38% more likely to be unaware of ACP, and black Americans were 38% more likely to not even consider ACP.⁵¹ Similarly, minorities are less likely to use hospice care⁵² but more likely to use futile “therapeutic” treatments.⁵³ The data manifests a general lack of knowledge about the existence of ACP and its function. An appropriate outreach program might bolster these numbers.

Historically, minority-majority areas have been deprived of medical resources. Of black Americans surveyed, nearly 50% had households below \$30,000 per year; of Hispanic Americans, that number was 34%.⁵⁴ Lower levels of income make it more difficult to pay for non-medically necessary services, such as ACP counseling. This naturally leaves black and Hispanic Americans with less access to ACP resources.

In the context of hospice care, that is no different; minority neighborhoods find hospice care to be near impossible when facilities and pharmacies are not in the area, and in-home

⁵⁰ Colette McAfee et al., *Predicting Racial & Ethnic Disparities in Advance Care Planning Using Integrated Behavioral Model*, 78 OMEGA J. OF DEATH & DYING 369 (2019).

⁵¹ *Id.* at 380.

⁵² Barbara Noah, *The Role of Race in End-of-Life Care*, 15 J. HEALTH CARE L. & POL’Y 349, 357 (2012).

⁵³ *Id.* at 355.

⁵⁴ McAfee et al., *supra* note 50, at 380.

providers (often required for in-home hospice) refuse to go to certain low-income neighborhoods where minorities have been relegated by the forces of de facto segregation.⁵⁵

This lack of knowledge is not strictly the result of inadequate outreach programs or inadequate resources. Minorities typically hold a negative attitude towards ACP.⁵⁶ These negative attitudes are warranted; studies have borne out bias – whether conscious or unconscious – in the medical establishment, as well as historic deprivation of medical resources in black American communities.⁵⁷ In particular, many black Americans feel that their doctors may recommend cessation of curative care prematurely, making that demographic more likely to enter hospice care at later disease stages.⁵⁸ Moreover, there exists a fear that doctors – a predominantly white professional demographic – will believe they know better than the black patient and will simply disregard a black patient’s wishes, even if manifested in an advance directive.⁵⁹ Unethical medical experimentation in the past may also influence this bleak outlook,⁶⁰ perhaps leading some to believe that they will be used to test new treatments or to see the durability of the human body if curative treatment is withdrawn. The history of discrimination in America has made black Americans much more doubtful of the benefit of ACP and hospice care when compared to white Americans.

Additionally, cultural considerations make it less likely for minorities to embrace ACP and hospice. As for Hispanic Americans, ACP and hospice are viewed as subversive of God’s plan for the patient.⁶¹ Similarly, black Americans believe life and death should be left up to God

⁵⁵ Alina M. Perez & Kathy L. Cerminara, *La Caja de Pandora: Improving Access to Care Among Hispanic & African American Patients*, 10 HOUS. J. HEALTH L. & POL’Y 255, 284 (2010).

⁵⁶ McAfee et al., *supra* note 50, at 381.

⁵⁷ Noah, *supra* note 52, at 362-63.

⁵⁸ *Id.* at 363.

⁵⁹ Perez & Cerminara, *supra* note 55, at 287.

⁶⁰ Perez & Cerminara, *supra* note 55, at 286.

⁶¹ Perez & Cerminara, *supra* note 55, at 274.

to decide.⁶² Hispanic Americans tend to believe that hospice care means giving up hope that God will save the patient.⁶³ Notably, Hispanic Americans conceive of a hospice as a place where one goes to die alone.⁶⁴

Language barriers also present a unique difficulty with the Hispanic community. In Spanish, “hospice” is the word for “orphanage.”⁶⁵ As a result, the word may confuse patients and family members who immediately associate “hospice” with a less-than-favorable setting and circumstance.

IV. The Academic Literature on Death and Care Planning

There is a thorough body of literature analyzing the difficulties in this area to both legislate and practice as a legal professional, a policymaker, and a physician. The literature identifies areas that need to be addressed in order to craft a policy that will better serve American patients’ needs; issues identified include (mis)conceptions about death, optics of such a program, lack of education, and poor communication.

Americans, as discussed, perceive death as inherently painful. There is an understandable hesitance to accept death as either an individual patient at the end of life or as a family member involved in deciding the fate of a loved one. However, there are benchmarks for what people consider a “good” death. For one, a good death is widely considered to be one where a patient experiences minimal pain.⁶⁶ A good death also allows more patient freedom and allows for

⁶² Perez & Cerminara, *supra* note 55, at 279.

⁶³ Perez & Cerminara, *supra* note 55, at 279.

⁶⁴ Perez & Cerminara, *supra* note 55, at 275.

⁶⁵ Perez & Cerminara, *supra* note 55, at 275.

⁶⁶ Deborah Carr, “*I Don’t Want to Die Like That*”: *The Impact of Significant Others’ Death Quality on Advance Care Planning*, 52(6) THE GERONTOLOGIST 771 (2012).

continued close relationships between patients and loved ones.⁶⁷ Further, understanding and accepting death naturally improves people's feelings about the inevitable.⁶⁸

There is a movement to increasingly provide patients with psychological counseling when facing the end of life.⁶⁹ This approach would treat patients as a "whole person" rather than a series of symptoms and maladies that must be addressed.⁷⁰

However, the importance and applicability of education on death reaches beyond the hospital bed. Nursing and medical students may well benefit from greater formalized education on death – and, by extension, patients and their families benefit. After learning more about death and dying in the hospital setting, nursing students demonstrated more positive attitudes when caring for dying patients,⁷¹ stemming from an acceptance that death is a possible and natural outcome.⁷² Greater comfort with this sensitive patient population may lead to a higher quality of treatment and, consequently, a higher quality of life at its end stages.⁷³ Nursing students who received education on the nature of death and its role in the Circle of Life resulted in better interactions with patients and patients' families by closing the communication gap that often forms between patients' families and nurses when patients are nearing death.⁷⁴

Similarly, the National Institute of Medicine (or "the NIM") noted the importance of palliative care education. Specifically, the NIM (now the Institute of Medicine) called for educational institutions, accrediting entities, and professional societies to provide or require

⁶⁷ *Id.*

⁶⁸ *Id.*

⁶⁹ *Id.*

⁷⁰ *Id.*

⁷¹ Judy L. Mallory, Ed.D., CHPN, *The Impact of a Palliative Care Educational Component on Attitudes Toward Care of the Dying in Undergraduate Nursing Students*, 19(5) J. OF PROFESSIONAL NURSING 7 (2003).

⁷² Birgül Cerit, *Influence of Training on First-Year Nursing Department Students' Attitudes on Death and Caring for Dying Patients*, 78(4) OMEGA J. OF DEATH AND DYING 335, 341-42 (2019).

⁷³ Mallory, *supra* note 71, at 7.

⁷⁴ Cerit, *supra* note 72, at 342.

education on palliative care to satisfy those organizations' accrediting standards.⁷⁵ The common thread throughout the literature and their scholarly recommendations is that greater education in the area of palliative care will lead to improved patient treatment quality.

Despite its importance, nursing and medical schools are not prioritizing palliative care and philosophical quandaries in death and healthcare. In one survey, most respondents polled (medical students, residents, and faculty) agreed that the physician is responsible for ensuring a sense of hope in terminal prognoses and treating the depression of dying patients.⁷⁶ While feeling responsible for this treatment, 39% of students and 31% of residents said they were either “not very well” or “not at all” prepared to address patients' concerns in regards to dying, with even greater numbers similarly ill-prepared for addressing cultural issues (55%, 59% respectively) and spiritual issues (49%, 54% respectively), as well as comforting bereaved family (46%, 37% respectively).⁷⁷ Within the hospital culture, treating a dying patient has been typically regarded as not rewarding for medical training, with 60% of students, 52% of residents, and 56% of professors reporting as such.⁷⁸

To understand how little attention is paid to such a common healthcare outcome, consider this: students reported palliative care received less attention in the classroom than *the rare autoimmune disease lupus*.⁷⁹

This tracks with the NIM's survey, which found nursing and medical students are provided minimal – if any at all – education on end-of-life care.⁸⁰ Generally, one must be enrolled in a palliative care concentration in order to receive any training; if one is fortunate, a

⁷⁵ THE NATIONAL INSTITUTE OF MEDICINE, IMPROVING QUALITY AND HONORING INDIVIDUAL PREFERENCES NEAR THE END OF LIFE: KEY FINDINGS 6 (2014).

⁷⁶ Sullivan, *supra* note 42, at 688.

⁷⁷ Sullivan, *supra* note 42, at 689.

⁷⁸ Sullivan, *supra* note 42, at 689-90.

⁷⁹ Sullivan, *supra* note 42, at 688.

⁸⁰ THE NATIONAL INSTITUTE OF MEDICINE, *supra* note 75, at 4; *see* Heilweil, *supra* note 8.

student may be able to take an elective course on palliative care.⁸¹ The result is medical professionals – at little fault of their own – left without the proper skillset to address complicated issues at end of life.

The NIM found that there is a lack of communication with patients in regards to palliative care.⁸² The NIM study concluded there is massive importance in improving communication skills as those skills are necessary to improve quality of death.⁸³ Communication is seemingly overlooked by educational institutions just as much as palliative care itself.

While it cannot be certain that less communication in this arena is harming patients in a traditional conception of harm, less communication is getting in the way of improved patient quality of life and quality of death. Patients with the best quality of life (and death) were those who opted for symptom-directed treatment, rather than life-extending treatment; an overwhelming majority of patients (83% of terminal patients) who recognized their conditions were terminal were more likely to accept symptom-direct care than the long-shot life-extending treatments offered.⁸⁴ Further, patients who turned down life-extending treatments experienced less physical distress in death.⁸⁵ The study concluded that patients who have opportunity to discuss their preferences at end of life are more likely to receive care consistent with their preferences, which leads to better quality of death.⁸⁶

The hypothesis that communication bears better quality of death in the end-of-life stages of disease is a proven one. In 1991, the local medical leaders of La Crosse, Wisconsin, began a program to encourage medical professionals and patients to discuss end-of-life wishes preceding

⁸¹ Heilweil, *supra* note 8, at 2.

⁸² THE NATIONAL INSTITUTE OF MEDICINE, *supra* note 75, at 4.

⁸³ THE NATIONAL INSTITUTE OF MEDICINE, *supra* note 75, at 6.

⁸⁴ Jennifer Mack et al., *End-of-Life Discussions, Goal Attainment, and Distress at the End of Life: Predictors and Outcomes of Receipt of Care Consistent with Preferences*, 28(7) J. OF CLINICAL ONCOLOGY 1203, 1206 (2010).

⁸⁵ *Id.* at 1203.

⁸⁶ *Id.*

a medical crisis.⁸⁷ The results were incredible: before the program, 15 percent of La Crosse residents who passed away had advance directives; by 1996, 85 percent of residents who passed on had advance directives.⁸⁸ Nearly all physicians knew of and followed these directives.⁸⁹ The discussions allow greater clarity in administering patients' wishes.⁹⁰ End-of-life care costs in La Crosse dropped and still remain low.⁹¹ During the last six months of life, elderly residents on average spend half as many days in the hospital as the national average.⁹² There may be concerns about undertreatment, but there is no indication that this decrease in costs is the result of treatment ending abruptly or improperly.⁹³

Communication is the clear pathway to meeting patients' wishes; patients' wishes are the best way to ensure a quality and graceful exit from this world. Without effective communication and counseling from medical professionals, patients will find it harder to understand their condition and their treatment options. A more robust dialogue ensures patients know their options and will make choices that better reflect their values, their goals, and their perception of what an acceptable quality of death might be.

V. The Current End-of-Life Legal Regime

A. Long-Term Planning in America Today

The only end-of-life planning service currently compensated by Medicare is advance care planning. However, only approximately 18% to 36% of adults in America have advanced care directives.⁹⁴ This is in spite of Medicare's existing provision compensating for advanced care

⁸⁷ GAWANDE, *supra* note 1, at 179.

⁸⁸ GAWANDE, *supra* note 1, at 179.

⁸⁹ GAWANDE, *supra* note 1, at 179.

⁹⁰ GAWANDE, *supra* note 1, at 180.

⁹¹ GAWANDE, *supra* note 1, at 179.

⁹² GAWANDE, *supra* note 1, at 179.

⁹³ GAWANDE, *supra* note 1, at 179.

⁹⁴ DEPARTMENT OF HEALTH AND HUMAN SERVICES, ADVANCED DIRECTIVES AND ADVANCE CARE PLANNING: REPORT TO CONGRESS 13 (2008).

planning.⁹⁵ The service may be provided as both part of the Annual Wellness Visit and a separate Medicare Part B medically necessary service.⁹⁶

To inform beneficiaries of Medicare benefits, the Centers for Medicare and Medicaid Services provides a yearly handbook entitled *Medicare & You*.⁹⁷ The 2020 edition spans 120 pages.⁹⁸ Despite its considerable length, it discusses hospice care, or “comfort” care as the handbook alternatively calls it, only in regards to eligibility requirements, an overview of covered services and products, and locations for service.⁹⁹ The handbook offers a brief description of hospice care: “When you agree to hospice care, you’re agreeing to palliative care (comfort care) rather than care to cure your illness.”¹⁰⁰ This does little to reassure patients. The handbook falls prey to the false dichotomy of “fight or give up,” when comfort care is truly about prioritizing different goals in treatment.¹⁰¹

The handbook also covers advance care planning. It informs readers that ACP is covered; it defines ACP as a voluntary method of ensuring a patient receives the care he or she would like if he or she becomes “unable to speak for [him- or herself].”¹⁰² It states the service is free to beneficiaries if utilized during a yearly wellness visit or subject to a Part B deductible and coinsurance if pursuant to medical treatment.¹⁰³ ACP, it notes, produces an advance directive, described as “an important legal document that records [one’s] wishes about medical treatment at a future time”¹⁰⁴

⁹⁵ CENTERS FOR MEDICARE AND MEDICAID SERVICES, FACT SHEET: ADVANCE CARE PLANNING 3 (2019).

⁹⁶ *Id.* at 2.

⁹⁷ See CENTERS FOR MEDICARE AND MEDICAID SERVICES, *MEDICARE & YOU* (2019).

⁹⁸ *Id.*

⁹⁹ *Id.* at 26-27.

¹⁰⁰ *Id.* at 26.

¹⁰¹ THE AMERICAN CANCER SOCIETY, *supra* note 14.

¹⁰² *Id.* at 30.

¹⁰³ *Id.*

¹⁰⁴ *Id.*

It is not immediately apparent why more Americans are not engaging in advance care planning with their physicians. Patients need not worry that they will pay a lot out-of-pocket for this service, and physicians are guaranteed compensation for providing the service. The hypothesized communication barrier is evidenced by this discrepancy between availability and low utilization; a physician may understandably feel uncomfortable asking an older patient about the circumstances in which, in the patient's view, the metaphorical "plug" should be pulled, especially if that physician is not equipped emotionally and rhetorically to discuss such an existentially sensitive topic.

B. The Patient Self-Determination Act of 1990

The Patient Self-Determination Act of 1990 (the "PDSA") amended the Medicare statute in a manner intended to strengthen the force of advance directives.¹⁰⁵ The bill requires written notice provided to patients upon admission to a health care facility of their decision-making rights, and policies regarding advance health care directives in their state and in the institution to which they have been admitted; patient rights that must be covered include the right to make one's own health care decisions, the right to accept or refuse medical treatment, and the right to make an advance directive.¹⁰⁶ Additional patient-centric mechanisms include the requirement that a treating facility ask a patient whether he or she already has an advance directive, and, if so, indicate such in the patient's records.¹⁰⁷

Other provider-centric mechanisms include the requirement that facilities provide education to their staff and affiliates about advance health care directives.¹⁰⁸ To ensure equal

¹⁰⁵ 42 USCA § 1395cc, P.L. 101-508, 104 Stat. 1388 (Nov. 5, 1990).

¹⁰⁶ *Id.* § 1395cc(a)(2).

¹⁰⁷ *Id.* § 1395cc(b).

¹⁰⁸ *Id.* § 1396a(a)(2).

care, the PDSA bars discriminatory admission or treatment of patients based on whether patients have an advance directive.¹⁰⁹

VI. Historic Proposed Changes to the Current End-of-Life Legal Regime

A. The Personalize Your Care Act of 2013

i. The Proposed Act and its Provisions

The Personalize Your Care Act (“PYCA”) sought to make patients more active participants in their care.¹¹⁰ The Findings of the Act note a study from the Agency for Healthcare Research and Quality which, following the trend of above cited studies, found less anxiety at the end of life when a patient discussed his or her values and desires for end-of-life care.¹¹¹ PYCA encouraged routine advanced care planning that is revisited periodically to reflect a patient’s changes in values at different stage of life.¹¹²

PYCA would have amended the Medicare and Medicaid statutes by altering voluntary ACP consultations.¹¹³ In these consultations, physicians “may” describe the role of advance directives as well as the different treatment options for end-of-life care, but such discussions are not required.¹¹⁴ The Act would have left the Secretary of the Department of Health and Human Services to decide whether these topics are to be mandatory parts of ACP.¹¹⁵ Consultations may be with physicians, nurse practitioners, or physician assistants.¹¹⁶

Reimbursement for ACP consultation would be paid for by Medicare only once every 5 years unless there is a significant change in health status or care setting.¹¹⁷

¹⁰⁹ *Id.* § 1395cc(a)(1)(C).

¹¹⁰ H.R. 1173, 113th Cong. § 1(b)(9) (2013).

¹¹¹ *Id.* § 1(b)(10).

¹¹² *Id.* § 1(a)(7).

¹¹³ *Id.* §§ 2(a)(1)(B), 2(b); for Medicaid specifically, ACP consultations would be mandatory benefits.

¹¹⁴ *Id.* § 2(a)(1)(B).

¹¹⁵ *Id.* § 2(a)(1)(B).

¹¹⁶ *Id.* § 2(a)(1)(B).

¹¹⁷ *Id.* § 2(a)(1)(B).

PYCA would further ensure patients' wishes are carried out by placing advance directives and current physician orders for life-sustaining treatment in patient files pursuant to rules promulgated by the Secretary.¹¹⁸ This ensures the patients' wishes are available for reference but does not require that the physicians carry out such wishes.

ii. Analysis of the Proposed Act

PYCA does quell some of the concerns identified by the literature, but still falls short. While not perfect, PYCA would have represented a step forward in end-of-life care. The proposed Act is fashioned to promote certain policy goals while remaining mindful of human nature.

For one, it would be shocking to people to require all Medicare and Medicaid beneficiaries to undergo ACP consultation. The legislation, if made compulsory, may draw comparisons to those much-discussed and universally feared "death panels."¹¹⁹ PYCA's voluntary ACP falls in line with literature that cautions against falling prey to the "death panel" label that leaves any such accused Act dead on arrival.

The encouragement to discuss not only advance directives but the options for end-of-life care theoretically provides patients with information on what to expect with life-extending treatment versus palliative care. However, the language must be stronger as to what sort of rules the Secretary is to promulgate. Making the information requirements permissible leaves too much discretion to the Secretary in carrying out the policy goals expressed in the Findings as well as meeting needs described in the psychological studies. Additionally, to bolster the efficacy of these disclosures, there must be some standard of information; the reasonable patient standard

¹¹⁸ *Id.* § 4(1), (2).

¹¹⁹ Patel, *supra* note 46, at 2.

may serve as a starting point, especially considering it is proven to be more effective at educating patients in shared decision-making.¹²⁰

The inclusion of patient advance directives or other ACP material in medical records is crucial to further the goal of patient autonomy seen in the literature. However, the Act does not go far enough. While making the advance directive available, PYCA does not make following the advance directives mandatory. To meet the goals of the scientific community and the Act itself, PYCA would absolutely have to give effect to the directives through a tort mechanism or a standard of care.

Seemingly aware of the importance of an interdisciplinary team in treating late-stage disease and/or elderly patients, PYCA would continue to compensate physicians, nurse practitioners, and physician assistants for ACP. Presumably, the drafters were aware that medical professionals other than physicians treat this patient population. While nodding to this reality, the drafters did not expand the pool of “qualified healthcare professionals.”

The Act would need to include a wider breadth of qualified health care professionals. A broader professional group covered allows more freedom to patients. This brings into the fold professionals who are practiced in discrete areas of end-of-life care. Given the amount of anxiety and depression experienced in terminal circumstances, it would be wise to include psychiatrists and social workers specializing in grief counseling or some similar area of psychology. These professionals might not aid in drafting the actual advance directive or the end-of-life care plan, but they may help ease a patient’s mind and help come to a result that is more in line with a patient’s values and goals at end of life.

¹²⁰ See Erica S. Spatz, MD, MHS, et al., *The New Era of Informed Consent: Getting to a Reasonable Patient Standard through Shared Decision Making*, J. OF THE AMERICAN MEDICAL ASSOCIATION, 3-4 (2016).

That the coverage provides ACP only once every five years (except in the event of the healthcare setting change or health status change) is limiting such that advance directives may be less accurate and up-to-date, particularly with Medicare beneficiaries. Medicare benefits only are available to individuals age 65 or older. People may want to more regularly revisit their care plan as they continue aging, after receiving other consultation, after witnessing loved ones receive end-of-life care, or any other myriad reasons. At the same time, small or progressive changes in health may occur within that 5 year period, especially as individuals age, that may not rise to the level that the Act contemplates. One may experience minor cognitive decline, which may not fit into the definition of “change in health status,” but still stir the patient into seeking a change in the advance directive or care plan; even within the cognitive decline paradigm, the trend of one’s diminishment does not follow an easily predictable trajectory, meaning a decline next year – or next month – may be more severe than any seen before by that individual. The inflexibility of the reimbursement regime proposed hampers reasonable efforts to respond to the signs of decline.

The presence of advance directives in health records as well as the guarantee that advance directives will be honored in all states both promote clear and consistent administration of a patient’s wishes. These mechanisms give life to the principle evidenced in the literature that patients experience greater quality of death when their wishes are effectuated.

B. The Care Planning Act of 2015

i. The Proposed Act and its Provisions

The Care Planning Act (the “CPA”), originally introduced to the Senate in 2015, is the more robust and better developed progeny of PYCA. The CPA borrows some elements from PYCA, but builds upon those elements to create a more comprehensive change to our current end-of-life legal regime; it elucidates the contours of the ACP discussion, identifies patient

populations who would benefit from such discussion, and protects physicians who carry out a patient's requested advance care plan. In addition, it provides funds and guidelines for a public outreach program that would begin to resolve some of the gaps in the information asymmetry between medical professionals and patients.

In its Findings section, the CPA notes a concern that is reflected in this thesis: Americans live longer but are experiencing more and more suffering caused by a life prolonged well into a late disease stage.¹²¹ The Findings emphasize the importance of palliative and hospice care, as well as the potentially successful models used in those two areas of medicine.¹²² These two areas are not without their shortcomings; as noted above, there is a serious lack of palliative care specialists. However, the Act suggests the federal government, with its buying power, should pressure institutions for improvement in this area.¹²³ The Findings imply that fear of tort liability may motivate overtreatment.¹²⁴ The Findings also key in on the lack of information available to patients about treatment plans. Improved communication addressing required topics like quality of life aids in facilitating information symmetry between doctors and patients.¹²⁵

This Act would allow consultation between a patient, or the patient's family in the case of an incapacitated patient, and one or more members of the interdisciplinary palliative care team.¹²⁶ The Act sought to have specialists explain disease trajectory, burdens of possible courses of treatment, and foreseeable future decisions, if the patient becomes incapacitated.¹²⁷

¹²¹ S. 1549, 114th Cong. § 2(2) (2015).

¹²² *Id.* §§ 2(7), 2(8).

¹²³ *Id.* § 2(9).

¹²⁴ *Id.* § 2(10).

¹²⁵ *Id.* § 2(12).

¹²⁶ *Id.* § 3(a)(2).

¹²⁷ *Id.* § 3(a)(2).

The Act also requires discussion of patients’ “goals of care, values, and preferences” in planning services.¹²⁸

Individuals eligible for the planning services include those with metastatic or locally advanced cancer, Alzheimer’s and other progressive dementias, and late stages of neuromuscular diseases, diabetes, kidney, liver, heart, gastrointestinal, cerebrovascular, and lung diseases.¹²⁹ Additionally, individuals who need assistance with two or more daily activities and have one or more serious or life-threatening illnesses or frailties.¹³⁰ Interestingly, the Act provides a catch-all which allows the Secretary of Health and Human Services to promulgate regulations that extend planning services to individuals “with a need for planning services due to a serious or life threatening illness or risk of decline in cognitive function over time.”¹³¹

Unlike PYCA, the CPA includes changes to the *Medicare & You* handbook that are meant to encourage consultation in the advance care planning and palliative care planning areas.¹³² Specifically, the Act calls for changes to the handbook which would inform patients about the manner in which personal preferences fit into care planning and advocates for earlier intervention in the care planning process that discusses different treatment options.¹³³

Borrowing from PYCA, CPA requires advance directives in patient health records.¹³⁴ The manner of implementation is substantially similar to PYCA.¹³⁵

The Act protects physicians and institutions from HHS penalties if the medical professional or entity acts according to a patient’s wishes to the extent reasonable.¹³⁶

¹²⁸ *Id.* § 3(a)(2).

¹²⁹ *Id.* § 3(a)(2).

¹³⁰ *Id.* § 3(a)(2).

¹³¹ *Id.* § 3(a)(2).

¹³² *Id.* § 5.

¹³³ *Id.* § 5(a)(3).

¹³⁴ *Id.* § 6.

¹³⁵ Compare S. 1549, 114th Cong. § 6 with H.R. 1173, 113th Cong. §§ 4(1), 4(2) (2013).

¹³⁶ S. 1549, 114th Cong. § 6(G).

A public outreach program would have been commissioned.¹³⁷ One provision involved developing an educational program for healthy individuals to begin considering advance care planning, particularly in regard to values and preferences, and advance directives.¹³⁸ Another provision sought to reach out to patients with advanced disease to better understand goals of care, disease trajectory, treatment options in light of goals of care, and developing and documenting a treatment plan.¹³⁹ Relatedly, the outreach program was meant to educate individuals on the range of services available, including ACP and end-of-life care.¹⁴⁰ The program also was to ensure patients were aware of the effectiveness of advance directives.¹⁴¹

ii. Analysis of the Proposed Act

This proposed Act sought to close the gap in treatment left by insufficient numbers of palliative care specialists and attending medical professionals inadequately trained in palliative care and related services. The invocation of the federal government's buying power serves that end by placing certain requirements on medical facilities receiving federal funds; the federal government already has requirements in place for facilities to qualify for receipt of Medicare dollars.

The Act notes – though does not legislate in response to – unfounded fears that physicians may be professionally liable for undertreatment, so physicians preemptively respond to such perceptions by encouraging overtreatment.¹⁴² The Act would protect physicians and

¹³⁷ *Id.* § 8.

¹³⁸ *Id.* § 8(a)(1)(A).

¹³⁹ *Id.* § 8(a)(1)(B).

¹⁴⁰ *Id.* § 8(a)(1)(D).

¹⁴¹ *Id.* § 8(a)(1)(C).

¹⁴² Even in cases where there is strong evidence of malpractice presented, physicians succeed in approximately 50% of cases; that number increases to 70% for “borderline cases” and up to 90% for weak cases. *See* Philips G. Peters, *Twenty Years of Evidence on the Outcomes of Malpractice Claims*, 467(2) *CLINICAL ORTHOPAEDICS AND RELATED RESEARCH* 352 (2008); *see also* Heather Lyu et al., *Overtreatment in the United States*, *PLOS ONE* (2017) (84.7% of physicians surveyed noted a fear of malpractice motivated overtreatment).

facilities from Department of Health and Human Services penalties that may arise from undertreatment carried out pursuant to a patient's advance directive but does not take any further steps.

Involving family and an interdisciplinary team in the decision-making process matches with the literature's advocacy of a robust and broad decisional body. The incorporation of family may, as one commentator has noted, encourage an outcome that favors the family members' preference to have more time, however painful,¹⁴³ but the involvement of an interdisciplinary team – coupled with the required discussion of disease trajectory, goals of care, and personal preferences – informs that understandable human response by informing the decision-making group of the reality of the health circumstances and consequences of protracted treatment.

The proposed Act offered the Secretary of Health and Human Services a catchall to expand the Act's provisions to those with serious illness or those with decline in cognitive function; this is much in line with the general consensus of what sorts of conditions should have more conscientious planning, though some conditions may require less intensive planning than others. However, amended Subsection (3)(F), under Section 3(a)(2) of the Act, has broad language that covers those with difficulties completing two or more daily activities and has one or more serious or life-threatening conditions. This scope may capture conditions that do not match with the statutory intent, such as cerebral palsy which is ultimately life-threatening after several decades and does impede daily activities, but which do not require planning for the very long-term of multiple decades; however, because the Act's ACP consultations would have been voluntary, despite this patient population possibly falling under the CPA's purview, the patients

¹⁴³ See GAWANDE, *supra* note 1, Ch. 6.

are by no means required to engage in this consultation. Rather, this may prove to be useful for that patient population later in life.

Again, as discussed in relation to PYCA's similar provision, placing advance directives in patients' medical records does help ensure clear and consistent administration of patients' wishes.

CPA would have provided a two-part public relations cure. The first cure would be amending the *Medicare & You* handbook to better discuss palliative care. As noted above, the 2020 edition briefly touches on the topic and may actually add to the anxiety around palliative care; it sounds more like giving up on a sick patient than comforting a sick patient.¹⁴⁴ This does little to reassure patients. The handbook falls prey to the false dichotomy of "fight or give up," when comfort care is truly about prioritizing different but equally important goals in treatment.¹⁴⁵ CMS must not proliferate that misconception and amend the handbook with more neutral language.

The Act sought to resolve the information asymmetry between medical professionals and patients by providing decision aids¹⁴⁶ that inform patients of options other than therapeutic treatment. In turn, this may provide patients with the tools they need to elect for earlier palliative care intervention rather than much later in the disease stages and, therefore, minimize pain and suffering over the long term – if the patient believes this to be appropriate.

This second public relations cure may be the most important aspect of this proposed bill as it addresses many of the shortcomings of the current system with an effective yet light touch.

¹⁴⁴ CENTERS FOR MEDICARE AND MEDICAID SERVICES, *supra* note 97, at 26 ("When you agree to hospice care, you're agreeing to palliative care (comfort care) rather than care to cure your illness.").

¹⁴⁵ THE AMERICAN CANCER SOCIETY, *supra* note 14.

¹⁴⁶ A decision aid is a tool meant to educate patients on available treatment options, particularly with regard to potential benefits and costs – both fiscal and physical – of such options. Decision aids encourage greater patient autonomy through informed, shared decision-making between patient and practitioner. *Decision Aids*, THE MAYO CLINIC CENTER FOR INNOVATION, <http://centerforinnovation.mayo.edu/decision-aids/>.

This function of the Act countered some of the key difficulties faced in ensuring widespread use of advance care planning and end-of-life care.

As stated above, adults with advance directives or any sort of long-term plan represent the minority of patients. The CPA gets ahead of the issue by bringing up these discussions before an individual becomes a patient; speaking with healthy individuals may be easier to get a thorough advance directive. However, healthy individuals have little incentive to put together an advance directive. Outreach may move us up from a quarter-or-so of Americans with a plan, because many Americans do not even know of advance care planning's existence or may be too unsure of its usefulness.

The program would also inform the most vulnerable group – those with advanced diseases – of their treatment options. The hope is that, with thorough information provided by a financially disinterested entity, a patient will make decisions that are more in line with the patient's goals and values thus leading to a happier patient. Patients would be educated on what to expect so, at a minimum, they know what they will be experiencing as the disease progresses, even if they opt to aggressively fight back within their right subject to the limitations of Medicare. Bringing the education full-circle, the program would advise patients on their options: palliative care, hospice care, therapeutic treatments – you name it.

Further, the program would address one of the unique difficulties in promoting advance directives among the black community. The Act's program counters one of the misconceptions in the black community that a physician may override a patient's advance directive. By informing individuals that a physician may not override the patient's wishes, even if the physician believes he or she knows better than the patient, a black patient may see the usefulness of an advance directive.

C. Beyond PYCA and the CPA

The proposed CPA reaches many of the issues identified in psychological studies of death and dying for Americans living with advanced diseases. The CPA comes the closest to addressing the key problems in this medical arena and should serve as the template for any bill that would amend the Medicare statute to better serve our patients. However, the CPA falls short in some important ways. Namely, it insufficiently provides for the mental health of terminal, chronically ill, or geriatric patients using life-sustaining treatments; it insufficiently provides resources for this patient population; and it does little to encourage treating physicians to comply with their patients' wishes.

One of the myriad issues with the current end-of-life care regime is at the very doorstep of the program: in order to qualify for hospice in particular, a patient must be certified to have a prognosis of six months or less to live.¹⁴⁷ However, as discussed above, a nontrivial minority of hospice patients live beyond six months.¹⁴⁸ With this in mind, and with the knowledge that physicians like those in *Agape Senior Community* believing it is reasonable to authorize hospice with a greater expected longevity, it would be sensible to promulgate regulations extending this to those who have expectancies of nine or even twelve months.

Closer to death, patients and families experience greater levels of anxiety and depression. The despair is well-placed; there is no greater existential bitter pill than death, whether one's own or that of a loved one. Because of this, any bill seeking to address end-of-life care must amend Medicare to cover counseling for the patient in his or her last days. The patient must be comfortable with the inevitable outcome of his or her terminal disease. Medicare must provide the proper tools to deal with the immense emotional distress associated with this reality.

¹⁴⁷ THE AMERICAN CANCER SOCIETY, *supra* note 14.

¹⁴⁸ NATIONAL HOSPICE AND PALLIATIVE CARE ORGANIZATION, *supra* note 18, at 13.

Furthermore, the CPA encouraged a greater number of palliative care specialists by leveraging the federal government's spending powers, but does not answer a practical question: Where will those palliative care specialists come from? There is presently a shortage of palliative care specialists, stemming from the lack of nursing and medical schools offering palliative care concentrations, certificates, or even dedicated classes.¹⁴⁹ To educate those with theoretical knowledge of palliative care but no practical knowledge, medical schools must also provide for more fellowship and residencies opportunities for those who wish to comfort the suffering.

To resolve the shortage and answer the command of the CPA, the federal government must similarly require medical and nursing schools receiving federal dollars to improve their palliative care educational offerings. Palliative care must be an offered concentration at all institutions. But, more importantly, more time in the classroom must be dedicated to educating future medical professionals on the availability of palliative care and when it is appropriate; time also should be spent teaching future medical professionals the appropriate communication techniques for those who will be treating dying patients or who may encounter death in the clinical setting.

Finally, there must be a twofold approach to incentivize physicians to treat patients in line with the patients' wishes. One, a carrot, must be some immunity to physicians for carrying out or recommending a symptom-direct treatment plan. The other, a stick, must create a tort for physicians who do not comply with a particular patient's wishes. Providing a starting point for such a tort is a California appellate court ruling that permitted a tortious "wrongful life" cause-

¹⁴⁹ THE NATIONAL INSTITUTE OF MEDICINE, *supra* note 75, at 4.

of-action for parents of a severely disabled child.¹⁵⁰ The Court reasoned that “a plaintiff both *exists* and *suffers*, due to the negligence of others.”¹⁵¹

Protections from liability must be extended to physicians who recommend palliative care. Of course, this will be incredibly difficult in practice; the protection would have to be carefully crafted so as to not immunize physicians who were actually negligent in their recommendation. Any litigation would develop into a battle of the experts; thus, for consistency, a statutory or regulatory standard must be devised. Traditionally, specialized and complex standards are set by agencies. Therefore, the Department of Health and Human Services should be left to devise this standard with some statutory guidance.

In addition, physicians must be penalized if they do not carry out a patient’s express wishes. If an advance directive is ignored because the doctor “knows better,” then that doctor must be subject to an administrative fine and professional reprimand. Given the literature on this topic, it will likely take little persuading for medical boards to join in penalizing rogue treating physicians. The stick of penalty will also serve the end of assuaging individuals who believe an advance directive may be ignored by a physician believing to know better.

It is important to take a moment to address the other issues with racial minorities and their difficulties with receipt of hospice care and their hesitation to engage in ACP. To the matter of hospice care, the Department of Health and Human Services must expand availability. At this time, the only option would be incentivizing Medicare-receiving hospice facilities and hospice providers with a bonus for operating in low-income areas; a minority-majority area bonus would be constitutionally impermissible under the Equal Protection clause, but a low-income area bonus is race-blind and would ideally expand access to all low-income patients.

¹⁵⁰ *Curlender v. Bio-Science Laboratories*, 106 Cal. App. 3d 811, 830 (Cal. App. 2nd Dist. Court of Appeal 1980).

¹⁵¹ *Id.* at 829. (emphasis in original)

Further, as noted above, the black and Hispanic American communities tend to be more religious and more likely to remain hopeful in the face of terminal disease. As a result, advance directives and palliative care are uncommon amongst these demographics. Despite this paper's position that futile therapeutic treatment often results in a lower quality of life, different viewpoints on acceptable qualities of life must be respected. Nothing should be done to force an individual to undergo treatment or lack thereof that is inconsistent with one's views; a strong and consistent belief both in this paper and the literature is that an individual's ultimate values and goals must be paramount and controlling in any care plan as those values and goals are ultimately what determine patient contentment and comfort.

VII. Conclusion

An issue as sensitive as end-of-life care needs an equally sensitive response, taking into consideration the individual difficulty and the differing viewpoints regarding such an existential matter. Thus, borrowing from proposed bills and building on existing statutes, this paper proposes an approach that provides information and education just as much as it provides comfort and reassurance – both legal and emotional.

To borrow from PYCA, routine advance care planning must be subsidized by Medicare, though to go beyond PYCA, that ACP must be available more frequently; those consultation sessions must cover specific crucial topics of discussion as to better inform patients under a reasonable patient standard. Advance directives must be placed in health records.

To borrow from the CPA, Congress must leverage its power of the purse to require facilities to provide greater access to palliative care specialists as part of an interdisciplinary team. Further recommended, though not covered by the CPA, is the inclusion of grief counselors or similar specialists on that interdisciplinary team. To facilitate implementation of advance

directives, physicians must be immunized from an alleged tort flowing from the physician reasonably following advance directive. In contrast, a tort must flow from a physician ignoring an advance directive. The last proposed change borrowed from the CPA is a comprehensive outreach program to better educate patients – even before they are patients; such a program must include an ACP outreach effort and rewriting portions of the *Medicare & You* handbook.

Lastly, Congress must find a way to meet the growing demand for palliative care specialists and the growing need for physicians who can address existential topics in the hospital and the examination room. Congress must require medical educational institutions receiving federal grants to establish more robust palliative care concentrations. Further, these institutions must educate their students on effective communication strategies for one of the most common healthcare outcomes and focus less on interesting rarities.

Through these proposed changes, Americans can better capitalize on their final days. Through better education, we make more informed decisions and have better informed consent. Through better communication with practitioners, we ensure our decisions that reflect our values are carried out. Ultimately, most of us would want to spend our last days doing what we love with who we love; through practical and informed treatment plans, Americans can do just that all while remaining relatively comfortable and living well into old age.