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A Step Toward Normalizing End-of-Life Care: Implications of the Palliative Care and Hospice Education and Training Act (PCHETA)

ROBERT BULANDA*

Despite their rapid development in recent decades, hospice and palliative care continue to face challenges to universal acceptance and access throughout American society, as the American population and medical professions are reluctant to move away from traditional preventative care throughout the death and dying process. The Palliative Care and Hospice Education and Training Act (PCHETA) is a federal bill seeking to increase access to palliative and hospice care. This Note analyzes the history of the palliative and hospice care movement and the implications of the PCHETA, arguing that the bill acts as an important step toward normalizing hospice and palliative care among the seriously and terminally ill population in the United States. Specifically, this Note argues that the PCHETA would sufficiently promote an increased workforce among hospice and palliative care professionals and recommends ways that the PCHETA could more sufficiently address the problems of low utilization of hospice care among racial, ethnic, and religious minorities, and the lack of education among health care professionals in end-of-life care and communication.

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I. INTRODUCTION

Demographic evolution and medical innovations combined with technological advances are facilitating an unprecedented growth in the aging and elderly population of the United States.¹ This growth flows, in part, from the aging of the nearly 78 million Americans born during the “Baby Boomer” generation, one of the largest population growth periods in United States history following World War II, from 1946 to 1964.² In addition to the numerical volume of aging Americans, medical and scientific advances and increasing health care choices are leading to increasing lifespans in the United States.³ These trends are leading to growth especially in the American population aged sixty-five and older for which Medicare provides “virtually universal” health care coverage.⁴ As of 2016, approximately 10,000 individual Americans turn sixty-five years old and age into the Medicare program every day, and this elderly Medicare population is expected to double over the next two decades.⁵ In 2016, Medicare provided health care coverage for 56.8 million people, including 47.8 million people aged sixty-five and older.⁶ In 2013, Americans aged sixty-five and older comprised approximately 14.1 percent of the total U.S. population.⁷ By 2030, the proportion of this age group is expected to increase to nearly 20 percent of the

1. Lynn Hallarman et al., *Blueprint for Success: Translating Innovations from the Field of Palliative Medicine to the Medical-Legal Partnership*, 35 J. LEGAL MED. 179, 181-182 (2014).

2. Matthew E. Misichko, *A HELP-ing Hand: How Legislation Can Reform the Affordable Care Act and Hospice Care to Prioritize and Prepare for the Baby Boomer Generation*, 21 ELDER L.J. 419, 452 (2014).

3. Naomi Cahn & Amy Zietlow, *Religion and End of Life Decision Making*, 2016 U. ILL. L. REV. 1713, 1723, 1736 (2016); Eriko Sase & Christopher Eddy, *The Millennials in an Aging Society: Improving End of Life Care by Public Health Policy*, 21 GEO. PUB. POL’Y REV. 1, 26 (2016).

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

5. Sue Ramthun & Jacqueline M. Kocinski, *Palliative Care & Hospice Education & Training Act: Momentum Continues to Build for AAHPM-Led Effort*, AAHPM QUARTERLY, <http://aahpm.org/quarterly/winter-16-feature> [https://perma.cc/D8CZ-PZPR].

6. BD. TR. FED. HOSP. INS. & FED. SUPP. MED. INS. TR. FUNDS, 2017 ANNUAL REPORT OF THE BOARDS OF TRUSTEES OF THE FEDERAL HOSPITAL INSURANCE AND FEDERAL SUPPLEMENTARY MEDICAL INSURANCE TRUST FUNDS 7 (2017).

7. Sase & Eddy, *supra* note 3, at 21.

total population,⁸ and it will continue to rise to approximately 21.7 percent by 2040.⁹ The ongoing and continuing rapid growth in the aging and elderly United States population has led some commentators to refer to the current population trend as the “silver tsunami.”¹⁰

This increasingly aging U.S. population raises concerns for end-of-life care and decision-making for Americans, including the elderly facing the management of chronic diseases and the process of death and dying.¹¹ The annual death rate in the United States is expected to double to approximately 4.1 million deaths per year by 2040.¹² Furthermore, members of the elderly population commonly experience one or more chronic illnesses prior to death.¹³ Despite the growing numbers of Americans facing the process of death and dying, the American cultural “aversion” to this process often prevents serious discussion and planning of end-of-life issues, especially in health care settings.¹⁴ Effective communication between physicians and patients about end-of-life care issues rarely occurs, in part because physicians are uncertain and apprehensive about discussing these issues,¹⁵ and in part because death is stigmatized and seen as a failure in traditional medical paradigms.¹⁶ Such lack of communication proves especially problematic in the United States, where “end-of-life care is a health care issue,” as opposed to a moral or legal issue.¹⁷

Hospice and palliative care offer potential solutions for the lack of effective end-of-life care communication. Hospice and palliative care are patient-centered models of care that address the physical, emotional, psychosocial, spiritual, and familial needs of patients and their families, utilizing inter-disciplinary teams of providers to focus on enhancing quality of life for seriously ill patients by anticipating, preventing, and treating suffer-

8. Misichko, *supra* note 2, at 452; Katherine B. Ledden, *A Nudge in the Right Direction with a Stick the Size of CMS: Physician-Patient Communication at the End of Life*, 6 ST. LOUIS U. J. HEALTH L. & POL'Y 389, 389 (2013).

9. Sase & Eddy, *supra* note 3, at 21.

10. Cahn & Zietlow, *supra* note 3, at 1723.

11. See, e.g., Cahn & Zietlow, *supra* note 3, at 1723 (describing their interest in how baby boomers are changing how Americans approach and experience the end of life).

12. Misichko, *supra* note 2, at 452.

13. Hallarman et al., *supra* note 1, at 181-82.

14. Abigail M. Lowin, *Changing the Means to Justify the End: Recommendations for the New York Palliative Care Information Act*, 49 COLUM. J.L. & SOC. PROBS. 167, 171 (2015).

15. Ledden, *supra* note 8, at 389, 402.

16. Kathleen Tschantz Unroe & Diane E. Meier, *Palliative Care and Hospice: Opportunities to Improve Care for the Sickest Patients*, 25 NOTRE DAME J.L. ETHICS & PUB. POL'Y 413, 416 (2011).

17. Lowin, *supra* note 14, at 170.

ing.¹⁸ Both models of care focus on “comfort care,” rather than curative care.¹⁹ Some commentators criticize this distinction as a “false dichotomy.”²⁰ Palliative care is available to all seriously-ill patients, while hospice is limited to terminally-ill patients with a physician’s prognosis of death within six months.²¹ Furthermore, patients electing hospice care must renounce aggressive curative efforts.²² Hospice began as a countercultural movement in the 1960s, protesting the “medicalization and over-technicality of death.”²³ Hospice’s emphasis on comfort care challenges traditional paradigms of American healthcare delivery,²⁴ as well as the broader “technological imperative” of American culture.²⁵ Palliative care developed as an outgrowth of hospice care throughout the 1980s and 1990s.²⁶ Over time, hospice and palliative care providers have grown in numbers and mainstream acceptance, as the humanitarian benefits of hospice and palliative care to patients and their families and their economic benefits of medical cost-savings have become widely recognized and understood.²⁷

18. NAT’L HOSPICE & PALLIATIVE CARE ORG., *Palliative Care and Hospice Education and Training Act*, HOSPICE ACTION NETWORK (2017), http://hospiceactionnetwork.org/linked_documents/get_informed/legislation/115/PCHETA_2017Overview.pdf [<https://perma.cc/3F6W-8T7A>].

19. Mary Rose Shelley, *Talking About the Taboo Topic of Death: State and Federal Initiatives to Reach Informed Consent at the End of Life Through Advance Care Planning*, 65 DRAKE L. REV. 583, 588-89 (2017).

20. Ryan A. Walsh, *A Matter of Life, Death, and Children: The Patient Protection and Affordable Care Act Section 2302 and a Shifting Legal Paradigm*, 86 S. CAL. L. REV. 1119, 1159-60 (2013). See generally Kathy L. Cerminara, *Hospice and Health Care Reform: Improving Care at the End of Life*, 17 WIDENER L. REV. 443 (2011).

21. Ledden, *supra* note 8, at 389. (Palliative care utilizes the hospice philosophy and holistic, team-based, interdisciplinary techniques to provide comfort care to seriously and terminally ill patients. However, the choice of palliative care does not necessarily require a six-month prognosis or refutation of curative care. See, e.g., J. Andrew Billings, *What is Palliative Care?*, 1 J. PALLIATIVE MED. 73 (1998)).

22. Cerminara, *supra* note 20, at 450.

23. *Id.* at 445.

24. Hallarman et al., *supra* note 1, at 180.

25. Hailey Akah, *Expanding the Scope of Bioethics Mediation: New Opportunities to Protect the Autonomy of Terminally Ill Patients*, 31 OHIO ST. J. ON DISP. RESOL. 73, 79 (2016).

26. Hallarman et al., *supra* note 1, at 181.

27. See generally Sase and Eddy, *supra* note 3, at 10-11 (summarizing studies demonstrating increased knowledge of hospice and palliative care among the general public); Joshua E. Perry & Robert C. Stone, *Cost and End-of-Life Care: In the Business of Dying: Questioning the Commercialization of Hospice*, 39 J.L. MED. & ETHICS 224 (2011) (highlighting the forty year evolution of hospice from a grass-roots movement to a multimillion dollar industry); Lainie Rutkow, *Optional or Optimal?: The Medicaid Hospice Benefit at Twenty*, 22 J. CONTEMP. HEALTH L. & POL’Y 107, 114 (2005) (asserting the humanitarian and economic benefits of hospice). See generally Sase & Eddy, *supra* note 3, at 10-11

Despite the growth and rising mainstream recognition of hospice and palliative care, they continue to face serious obstacles in providing care to the seriously and terminally ill. Physicians and other health care workers are not entering the fields of hospice and palliative care in sufficient numbers.²⁸ In general, health care professionals also continue to avoid discussing end-of-life issues with patients.²⁹ Furthermore, racial, ethnic, and religious minorities proportionately underutilize hospice care because of historical, economic, and cultural factors.³⁰

The Palliative Care and Hospice Education and Training Act (PCHETA) addresses some of these problems. The PCHETA is a federal bicameral, bipartisan bill seeking to address the problem of the lack of medical professionals going into the fields of palliative and hospice care by incentivizing the development of palliative and hospice care coursework, faculty, medical schools, and other health care professional schools.³¹ In introducing the original version of the bill in the Senate in 2013, Senator Ron Wyden stated that he believed that, if enacted, the bill would “address the workforce gap between those currently practicing in palliative care and hospice and the number of health care professionals required to care for this expanding patient population.”³²

Part II of this article analyzes the history of hospice and palliative care in the United States. It focuses primarily on its evolution from a countercultural grassroots movement into a widely accepted comfort care model for the seriously and terminally ill by medical professionals, policy makers and the general public. Part III of this article analyzes the problems of the current model of hospice and palliative care within the context of the American health care system. It focuses on the problems of low utilization of hospice care among racial, ethnic, and religious minorities, the lack of a sufficient workforce among hospice and palliative care professionals, and the lack of

(summarizing studies demonstrating increased knowledge of hospice and palliative care among the general public); Joshua E. Perry & Robert C. Stone, *In the Business of Dying: Questioning the Commercializing of Hospice*, 39 J. L. MED. & ETHICS 224 (2011) (highlighting the forty-year evolution of hospice from a grassroots movement to a multimillion-dollar industry); Lainie Rutkow, *Optional or Optimal?: The Medicaid Hospice Benefit at Twenty*, 22 J. CONTEMP. HEALTH L. & POL'Y 107, 114 (2005) (asserting the humanitarian and economic benefits of hospice).

28. Shelley, *supra* note 19, at 612; Nat'l Hospice & Palliative Care Org., *supra* note 18.

29. Shelley, *supra* note 19, at 585.

30. Rutkow, *supra* note 27, at 136; *see generally* Cahn and Zietlow, *supra* note 3; Barbara A. Noah, *The Role of Race in End-of-Life Care*, 15 J. HEALTH CARE L. & POL'Y, 349 (2012); Alina M. Perez & Kathy L. Cerminara, *Race and Healthcare in America: La Caja de Pandora: Improving Access to Hospice Care Among Hispanic and African-American Patients*, 10 HOUS. J. HEALTH L. & POL'Y 255 (2010).

31. H.R. 1676, 115th Cong. (2017); S. 693, 115th Cong. (2017).

32. 113 CONG. REC. S2149 (daily ed. Mar. 21 2013) (statement of Sen. Wyden).

education among health care professionals in end-of-life care and communication. Part IV of this article describes the PCHETA. It focuses on the legislative history and goals of the current bills in the United States House of Representatives and the Senate. Part V analyzes the strengths and weaknesses of the PCHETA in addressing the identified problems with access to hospice and palliative care in the United States and provides recommendations for how to further address these problems. It focuses on the strength of the proposed legislation in promoting strengthened education and workforce in hospice and palliative care, as well as its weakness in promoting end-of-life discussion skills among all health care professionals, students, and its weakness in addressing racial, ethnic, and religious disparities in access to hospice care.

This note argues that the PCHETA represents a step in improving palliative and hospice care in the United States because it strongly supports further development of a professional healthcare workforce dedicated to providing appropriate care for individuals with life-threatening illnesses. However, further steps will need to be taken to directly address the problem of lack of communication between healthcare professionals and patients regarding end-of-life issues, and the problem of lack of access to hospice care by racial, ethnic, and religious minorities.

II. HISTORICAL OVERVIEW OF HOSPICE AND PALLIATIVE CARE IN THE UNITED STATES

The American hospice movement began as a countercultural movement—albeit within the dominant white middle class³³—within the general background of the social upheaval of the 1960s.³⁴ Its origins trace to a lecture by British physician Dame Cecily Saunders, considered the founder of the modern hospice movement,³⁵ at Yale-New Haven Hospital in 1963.³⁶ The publication of Elisabeth Kubler-Ross's influential book *On Death and Dying* in 1969 further introduced hospice into the American sociocultural landscape.³⁷ The first hospice in the United States opened in New Haven, Connecticut in 1974.³⁸ In 1978, the National Hospice Organization formed to standardize the rules of hospice care and began lobbying efforts for national legislative regulations and funding for hospice care and services.³⁹ Such lobbying efforts led to the funding of twenty-six hospice demonstra-

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33. Rutkow, *supra* note 27, at 136.
 34. Cerminara, *supra* note 20, at 445.
 35. Unroe & Meier, *supra* note 16, at 417.
 36. Rutkow, *supra* note 27, at 109-10.
 37. *Id.* at 110.
 38. *Id.* at 110-11.
 39. *Id.* at 111.

tion projects throughout the United States by the Health Care Financing Administration in 1980.⁴⁰ These projects facilitated recognition among federal policy makers of hospice care as a health care option, and they led to the commissioning of the National Hospice Study.⁴¹ The purpose of this commission was “to evaluate the feasibility of introducing hospice as an option for Medicare reimbursement of terminal care.”⁴² While the study’s results were not available until 1985, Representative Leon Panetta and Senator Robert Dole introduced bills in the United States House of Representatives and Senate in late 1981 and early 1982 that proposed covering hospice care under Medicare for terminally ill patients.⁴³ The Medicare Hospice Benefit was codified as part of the Tax Equity and Fiscal Responsibility Act of 1982.⁴⁴ The Medicare Hospice Benefit reimburses hospice expenses for patients who meet three criteria.⁴⁵ The patient must be eligible for Medicare benefits in general, the patient must be “terminally ill,” and the patient must elect Medicare coverage of hospice care by waiving Medicare coverage of curative care and signing a statement acknowledging that “certain Medicare services...are waived by the election [of hospice care].”⁴⁶ The election of hospice care entitles patients to certain rights, including the right to receive effective pain management and symptom control, the right to be involved in developing their hospice plans of care, and the right to refuse care or treatment.⁴⁷ The Hospice Benefit is covered under Medicare Part A, which automatically enrolls eligible individuals who have paid into Social Security for forty quarters or more.⁴⁸ In 2014, nearly half (about 48 percent) of all Medicare decedents received care from a hospice program, including more than 1.3 million Medicare beneficiaries who received care in 4,025 Medicare-certified hospices.⁴⁹

The passage of the Medicare Hospice Benefit stemmed from both the “humanitarian appeal” of hospice care, and hospice care’s potential to decrease health care costs.⁵⁰ While the Medicare Hospice Benefit has re-

40. *Id.* at 112.

41. Rutkow, *supra* note 27, at 112-13.

42. *Id.* (quoting Ann C. Petrisek & Vincent Mor, *Hospice in Nursing Homes: A Facility-Level Analysis of the Distribution of Hospice Beneficiaries*, 39 GERONTOLOGIST 279, 280 (1999)).

43. Rutkow, *supra* note 27, at 113.

44. *Id.* at 114.

45. Cerminara, *supra* note 20, at 446.

46. *Id.* (quoting 42 C.F.R. § 418.3 (2010)).

47. 42 C.F.R. §418.52(c)(1)-(3) (2010). *See also* NICOLE HUBERFELD ET AL., THE LAW OF AMERICAN HEALTH CARE 578 (1st ed. 2016).

48. HUBERFELD ET AL., *supra* note 47, at 50, 51. *See also* 42 U.S.C.S. § 1395d (a)(4) (LEXIS through Pub. L. No. 115-117).

49. H.R. 1676, 115th Cong. § 2(2) (2017); S. 693, 115th Cong. § 2(2) (2017).

50. Rutkow, *supra* note 27, at 114.

mained largely unchanged since it was introduced in 1983,⁵¹ both the humanitarian and cost-savings benefits of hospice have continued to grow. In furtherance of humanitarian goals, studies demonstrate that patients who utilize hospice care experience greater quality of life at the end of life by providing psychosocial and spiritual care to patients and their families, and also by focusing care in the patients' homes rather than institutionalized environments.⁵² Hospice is "[c]onsidered the model for quality compassionate care for individuals facing a life-limiting illness."⁵³ In furtherance of cost-savings goals, hospice care has been demonstrated to reduce healthcare costs because it prevents excessive expensive hospital care, aggressive technological intervention, acute crisis health care, and referrals to hospitals and nursing facilities.⁵⁴

Both hospice and palliative care, which has grown out of the hospice movement, have received increasing recognition in recent years. Health professional associations, including the American Society of Clinical Oncology and the American Heart and American Stroke Association, increasingly recommend palliative care services for patients with advanced illnesses, and the Institute of Medicine recommends routine access to palliative care services to all Americans with advanced illness.⁵⁵ Almost all large hospitals and academic medical centers provide access to hospital palliative care programs.⁵⁶ In 2006, hospice and non-hospice palliative medicine were formally recognized by the American Board of Medical Subspecialties (ABMS) and the Accreditation Council for Graduate Medical Education (ACGME).⁵⁷ Furthermore, in October of 2008, the Centers for Medicare and Medicaid Services (CMS) officially recognized hospice and palliative medicine as a medical subspecialty.⁵⁸ Additionally, recognition of hospice care is growing within general American culture, as a recent study demonstrated that 86 percent of respondents were knowledgeable of the term "hospice."⁵⁹ However, while palliative care is one of the fastest growing fields of health care in the United States, only 10-20 percent of respondents were knowledgeable of the term "palliative care."⁶⁰ Additionally, the numbers of both hospice centers and patients are increasing. In recent years,

51. Gillick, *supra* note 4, at 29.

52. Walsh, *supra* note 20, at 1139; *see generally* Cerminara, *supra* note 20.

53. H.R. 1339, 113th Cong. § 2(3) (2013); S. 693, 115th Cong. § 2(2) (2017).

54. Rutkow, *supra* note 27, at 128.

55. Katherine A. Ornstein et al., *Families Caring for an Aging America Need Palliative Care*, 65 J. AM. GERIATRICS SOC. 877, 878 (2017).

56. *Id.* at 878.

57. Hallarman et al., *supra* note 1, at 182-83.

58. H.R. 1676, 115th Cong. § 2(5) (2017); S. 693, 115th Cong. § 2(5) (2017).

59. Sase & Eddy, *supra* note 3, at 7.

60. *Id.* at 8, 11.

over 1,000 new hospice centers have opened and patient use of the Medicare Hospice Benefit has increased by approximately 12 percent.⁶¹

However, rates of palliative care and hospice care health care professionals are projected to remain relatively low in comparison to the increase in rates of seriously and terminally ill patients. Despite the availability of palliative care and hospice care programs in large hospitals, timely referrals to these programs remains infrequent.⁶² As of February of 2017, the ACGME has accredited a total of 127 hospice and palliative medicine training programs, which were training 327 physicians in hospice and palliative medicine for the 2016-2017 academic year.⁶³ However, this number remains inadequate to address the “large gap between the number of health care professionals with palliative care training and the number required to meet the needs of the growing population of individuals with serious or life-threatening illness.”⁶⁴ Furthermore, a 2017 George Washington University Healthcare Institute study estimates a growth rate of no more than one percent in palliative care and hospice physician workforce in the next twenty years, while seriously ill patients eligible for palliative care will increase by more than twenty percent.⁶⁵ Under these projections, there will be one palliative care physician for every 26,000 eligible patients by 2030.⁶⁶

III. PROBLEMS OF THE CURRENT HOSPICE CARE MODEL

Indeed, despite the recent growth of hospice and palliative care programs and numbers of beneficiaries throughout the United States along with growing recognition of the benefits of hospice for the care of terminally ill patients and their caregivers, several structural problems with the current hospice care model continue to impede its potential growth within the American health care system. These problems cause terminally-ill patients to fail to access hospice care or access it too late to fully enjoy its benefits. They include disproportionately low access of hospice care among racial, ethnic, and religious minorities, an insufficient end-of-life care professional workforce, and lack of education of physicians and other health care professionals in end-of-life care and communication.

61. Misichko, *supra* note 2, at 430.

62. Ornstein et al., *supra* note 55, at 878.

63. H.R. 1676, 115th Cong. § 2(4) (2017); S. 693, 115th Cong. § 2(4) (2017).

64. H.R. 1676, 115th Cong. § 2(7) (2017); S. 693, 115th Cong. § 2(7) (2017).

65. Letter from Edo Banach, President & CEO, Nat'l Hospice & Palliative Care Org., to Tammy Baldwin, et al. 1 (Mar. 29, 2017), http://hospiceactionnetwork.org/linked_documents/get_informed/legislation/115/Letter_Support_PCHETA.pdf [<https://perma.cc/G3MF-A8GD>].

66. *Id.*

A. LOW RATES OF ACCESS OF HOSPICE CARE AMONG RACIAL, ETHNIC, AND RELIGIOUS MINORITIES

Several systemic factors contribute to the underutilization of hospice care among racial, ethnic, and religious minorities. These factors include a historically-rooted mistrust of the healthcare profession among minority populations, a lack of hospice resources in minority communities, and the cultural value systems of minority populations.

1. *Historically-Rooted Mistrust of the Healthcare Profession Among Minority Populations*

While hospice care developed in the United States as a countercultural movement throughout the socially turbulent decades of growing civil rights and racial consciousness of the 1960s and 1970s, it centered on the dominant culture of the white, middle-class community.⁶⁷ These historical roots continue to influence the lack of diversity within hospice care as “some still view” hospice as a “white, middle-class movement,” while “[m]any hospices are unable or unwilling to serve diverse populations.”⁶⁸ African-American and Hispanic populations, in particular, utilize hospice care in much lower numbers and much later than white populations.⁶⁹ For example, one recent study found that only eleven percent of minority decedents, compared with seventeen percent of white decedents utilized hospice care, and patients with higher socioeconomic status and stability were more likely to utilize hospice care.⁷⁰ Indeed, current “[h]ospice patients are predominantly white, mostly female, and overwhelmingly old,”⁷¹ while “[f]ewer racial minorities are enrolled in or take advantage of the Medicare hospice benefit.”⁷² Such disparities are particularly troublesome because ethnic and racial minorities suffer disproportionately from certain cancers and other chronic diseases.⁷³ Furthermore, “[d]isparities exist not only in the distribution of disease, but also in access to services, quality of care, treatment of various conditions, insurance status, and health outcomes.”⁷⁴ Within the field of hospice, studies demonstrate that African American and Hispanic populations are less likely than white or Asian populations to have adequate communication with physicians about hospice care.⁷⁵ This disparity in ac-

67. Rutkow, *supra* note 27, at 136.

68. *Id.*

69. Cerminara, *supra* note 20, at 456; Perez & Cerminara, *supra* note 30, at 257.

70. Teneille R. Brown, *Denying Death*, 57 ARIZ. L. REV. 977, 1015, FN 200 (2015).

71. Ledden, *supra* note 8, at 393.

72. Brown, *supra* note 70, at 1015.

73. Perez & Cerminara, *supra* note 30, at 257-58.

74. *Id.* at 282-83.

75. *Id.* at 275, 280.

cess to hospice care reflects a larger systemic trend of disparate quality of care for patients with life-threatening diseases based on racial, ethnic, and socioeconomic factors.⁷⁶ While hospice utilization among minority and poorer communities is increasing, white and more economically stable patients continue to receive the majority of hospice care.⁷⁷ Furthermore, despite the dramatic overall growth of hospice care, accessibility of hospice care varies among geographic and racial and ethnic groups.⁷⁸ Reasons for the current lack of diversity within hospice care include historical mistrust of the medical profession among minorities, especially African Americans; lack of diversity among medical professionals; a wealth and resource gap among racial and ethnic minorities; and cultural and religious differences between white majority culture and minority cultures, especially African American and Hispanic cultures.⁷⁹

Generally, racial and ethnic minority populations, especially African American populations, experience a deeply rooted historical and continuing mistrust of the American medical system.⁸⁰ For example, one recent study found that fifteen percent of racial minority patients and thirty-two percent of African American patients believed they would receive better care if their race or ethnicity were different.⁸¹ The deep history of slavery, segregation, and a century of unethical medical experimentation on African American communities has influenced a fear and mistrust of the medical establishment among these communities.⁸² Furthermore, “research suggests that African American and Hispanic patients are less likely to trust their physicians because of perceived discrimination, the legacy of racial discrimination in medicine and medical research, and social distance between physicians and their minority patients.”⁸³

Distrust of the American medical system in general leads patients within racial and ethnic minority and low socioeconomic status communities to distrust the purported benefits of hospice care in particular.⁸⁴ These populations, often receiving or holding the belief that they receive inferior

76. Sean O’Mahony et al., *A Review of Barriers to Utilization of the Medicare Hospice Benefits in Urban Populations and Strategies for Enhanced Access*, 85 J. URB. HEALTH 281, 283 (2008).

77. *Id.* at 284.

78. Unroe & Meier, *supra* note 16, at 424.

79. See, e.g., Perez & Cerminara, *supra* note 30, at 306-07. (“Generally speaking, patients of Hispanic and African-American backgrounds in particular differ in significant ways from Caucasian patients, around whose values and belief systems Western medicine and law generally have developed.”).

80. Noah, *supra* note 30, at 360.

81. O’Mahony et al., *supra* note 76, at 284.

82. Perez & Cerminara, *supra* note 30, at 286-87.

83. Noah, *supra* note 30, at 361.

84. Cerminara, *supra* note 20, at 456.

health care throughout their lives, are more likely to perceive hospice care as inferior care to aggressive curative care, and this perception leads to fears that hospice is a method of “rationing care” by the medical establishment.⁸⁵ Hospice care, with its “accompanying termination of curative efforts, represents a decrease in care from at least one perspective, thus likely representing an unacceptable choice to persons who resist decreases in care.”⁸⁶ Many minority patients, especially among African American populations, elect hospice care late out of fear that the cessation of therapeutic care is premature when it is initially advised by a physician.⁸⁷ Furthermore, “racism and discrimination” has contributed to a “fatalistic and pessimistic” belief system toward end-of-life care “in conflict with the hospice philosophy,” especially among African American populations.⁸⁸ Statistics demonstrate that populations with less access to quality health care prior to the end of life are more likely to pursue aggressive and expensive care at the end of life when it becomes more available.⁸⁹ “Unsurprisingly, minority patients who have less access to preventive measures are more reluctant to choose ‘nonaggressive’ measures at the end of life.”⁹⁰ For example, one recent “analysis of Medicare claims data indicated that costs for [end-of-life] care for racial minorities were 18% *higher* in the last year of life but 25% *less* in the three years prior to death.”⁹¹ Furthermore, in the final six months of life, health care spending was thirty-two percent higher for African American patients and fifty-seven percent higher for Hispanic patients compared with white patients.⁹² The receipt of aggressive care at the end of life correlates with low use of hospice, and this reversal of Medicare spending at the end of life demonstrates racial minorities’ pursuit of expensive and aggressive curative care when it is available.⁹³ However, counterintuitively, these expensive and aggressive measures at the end of life lead to worse outcomes for terminally-ill patients, as higher healthcare expenditures at the end of life are correlated with a lower quality of death.⁹⁴ For example, while aggressive curative care is “intuitively desirable,” it leads to a majority of deaths in the United States occurring in institutions, such as hospitals and nursing homes.⁹⁵ Such deaths in hospitals are especially prevalent among

85. *Id.* at 456.

86. Perez & Cerminara, *supra* note 30, at 287.

87. Noah, *supra* note 30, at 363.

88. Perez & Cerminara, *supra* note 30, at 287.

89. Brown, *supra* note 70, at 1015.

90. O’Mahony et al., *supra* note 76, at 284.

91. Brown, *supra* note 70, at 1015.

92. Noah, *supra* note 30, at 358.

93. Brown, *supra* note 70, at 1015.

94. Hallarman et al., *supra* note 1, at 190.

95. Walsh, *supra* note 20, at 1127.

African American populations, despite a generally stated preference to die at home among these populations.⁹⁶

Distrust of the medical establishment and lack of communication regarding hospice care among minority populations relates to the lack of minority medical and healthcare professionals.⁹⁷ The current “lack of providers from minority groups” demonstrates “a healthcare system that fails to address the needs of minorities.”⁹⁸ While minorities comprise approximately twenty-five percent of the United States’ population, only about nine percent of physicians belong to minority populations.⁹⁹ Analysis of the 2004 Sullivan Commission on Diversity in the Healthcare Workforce demonstrates that minority populations are underrepresented throughout the healthcare profession and faculty of academic healthcare programs.¹⁰⁰ This current underrepresentation of minorities within healthcare professions is likely to continue as the proportion of underrepresented minorities applying to medical schools has decreased since the mid-1990s.¹⁰¹

The lack of minority representation within the healthcare workforce hinders communication between members of minority populations and healthcare professionals. For example:

minority professionals may experience less difficulty than members of the healthcare professions from other backgrounds in understanding the cultural influences on patients of their same racial or ethnic background. Non-minority healthcare professionals may learn to appreciate such influences through exposure to them and training about them, but patients requiring hospice services are still more likely to interact with healthcare professionals in a meaningful way if they share their own racial or ethnic background.¹⁰²

96. Perez & Cerminara, *supra* note 30, at 279-80.

97. See, e.g., *Id.* at 299. (“There is a lack of congruence between hospice policies and the realities of caregiving in many Hispanic and African-American households, a shortage of minority physicians and other healthcare professionals in the system, a general failure to appreciate cultural differences among healthcare professionals, and a shortage of interpreters who deal with the end-of-life issues of the United States’ culturally diverse population.”)

98. *Id.* at 284.

99. *Id.* at 301.

100. *Id.* at 301-302. (“[O]nly nine percent of the nation’s nurses and five percent of dentists are from such [populations of] minorities, [and] only ten percent of baccalaureate nursing faculty, 8.6 percent of dental and 4.2 percent of medical faculty belong to a minority group.”)

101. Perez & Cerminara, *supra* note 30, at 301.

102. *Id.* at 302.

These communication problems prove especially problematic for immigrant and non-English-speaking minorities, especially Spanish-speaking Hispanic populations because language barriers between patients and healthcare professionals consistently negatively impact the healthcare process and ratings of quality of care, while language concordance correlates with positive healthcare experiences.¹⁰³ This language barrier is exacerbated by “a shortage of interpreters who deal with the end-of-life issues of the United States’ culturally diverse population.”¹⁰⁴ Culture and language barriers hinder access to hospice care because culturally and linguistically appropriate communication facilitates end-of-life care discussions and decision-making, especially in the election of hospice care.¹⁰⁵ According to a recent study, minority patients were less likely than white patients to have heard of hospice from their primary medical providers.¹⁰⁶ Additionally, once hospice care has been elected, appropriate communication facilitates quality of care and a positive hospice experience.¹⁰⁷ Furthermore, the traditional lack of diversity and cultural sensitivity to diverse communities among hospice teams in general provides a barrier to hospice care for minorities.¹⁰⁸

2. *Lack of Hospice Resources Among Minority Communities*

In addition to cultural and linguistic misunderstandings, the lack of minority representation within the healthcare workforce limits the accessibility of healthcare for minority populations because “minority professionals are more likely to practice in minority or medically underserved communities.”¹⁰⁹ Thus, the lack of minority healthcare professionals correlates with the lack of healthcare providers in underserved communities.¹¹⁰ African American and Hispanic communities are more likely than white communities to rely on emergency room care and clinics than a regular physician, leading to a lack of continuity of care among these minority populations, which hinders end-of-life diagnoses, end-of-life care discussions, and physician referrals to hospice care.¹¹¹ The lack of continuity of care espe-

103. *Id.* at 276.

104. *Id.* at 299.

105. *Id.* at 285.

106. O’Mahony et al., *supra* note 76, at 285.

107. Perez & Cerminara, *supra* note 30, at 285.

108. O’Mahony et al., *supra* note 76, at 284.

109. Perez & Cerminara, *supra* note 30, at 302.

110. *Id.* at 284.

111. *Id.* at 294.

cially hinders hospice access because of the hospice requirement that a primary care provider agree to a prognosis of six months of life or less.¹¹²

Furthermore, minority neighborhoods lack adequate hospice services and resources.¹¹³ Hospice programs and organizations are often located in the “better part of town,” away from poor communities and communities of color.¹¹⁴ Furthermore, inpatient hospice beds are often unavailable in economically marginalized areas of cities.¹¹⁵ Recent studies have demonstrated that Medicare beneficiaries “who resided in areas with zip codes with lower average incomes and higher rates of poverty had higher end-of-life expenditures and likelihood of dying in the hospital and lower rates of utilization of hospice.”¹¹⁶

3. *Cultural Value Systems Among Minority Populations*

In addition to systemic healthcare policy and economic factors contributing to the underutilization of hospice care by minority populations, significant barriers to hospice utilization also stem from cultural factors, especially among African American and Hispanic populations.¹¹⁷ In general, many “[i]ssues in health disparities and health illiteracy relate to racial, cultural, and religious insensitivity and barriers.”¹¹⁸ Culture influences healthcare and end-of-life decision-making because it influences patients’ perceptions of the role of healthcare professionals, their communication styles with professionals, and the values underlying their communications, decisions, and the outcomes of these decisions.¹¹⁹ Most important to the utilization of hospice care “culture has a tremendous impact on how people conceptualize and deal with pain” and “views of death, dying, and care at the end of life.”¹²⁰ Culture influences many aspects of end-of-life decision-making, especially “the communication of bad news” and “the locus of decision-making.”¹²¹ These cultural influences on end-of-life decision-making greatly affect Hispanic and African American populations in particular because of these cultures’ emphasis on family systems and religious belief.¹²²

112. O’Mahony et al., *supra* note 76, at 285.

113. Perez & Cerminara, *supra* note 30, at 283.

114. Rutkow, *supra* note 27, at 136.

115. O’Mahony et al., *supra* note 76, at 285.

116. *Id.* at 283-84.

117. Perez & Cerminara, *supra* note 30, at 258.

118. Sase & Eddy, *supra* note 3, at 14.

119. Perez & Cerminara, *supra* note 30, at 261.

120. *Id.* at 262.

121. *Id.* at 268.

122. *Id.* at 271, 278.

Familism reflects Hispanic culture's emphasis on the importance of family and a family system approach to healthcare decision-making.¹²³ Its placement of the family at the center of decision-making processes stands in contrast to the value of individual autonomy, the "preeminent value in modern American culture."¹²⁴ Familism may influence Hispanic family members to avoid informing a terminally-ill patient of his or her diagnosis out of fear that disclosing the terminal diagnosis to the patient may harm him or her.¹²⁵ Such avoidance of truth-telling, combined with a family approach to decision-making, hinders utilization of hospice care because it can remove the individual patient from the decision-making process, and the individual patient is responsible for electing hospice care under the current autonomy-based medical system.¹²⁶ Familism also places a high emphasis on hierarchy, leading many patients within the Hispanic population to defer to physicians and other healthcare professionals, which may further remove individual patients from the decision-making process and election of hospice care.¹²⁷ African American culture also places great importance on community and honoring the family, and this cultural value is at odds with the "patient-centered, autonomy-guided, healthcare values predominant in the American healthcare system."¹²⁸

Furthermore, the prevalence of religious belief among minority populations contributes to their reluctance to utilize hospice care and forego curative care.¹²⁹ Many terminally-ill Hispanic patients are reluctant to forego curative care and elect hospice care because of their religious view that "life is a gift from God" to be preserved as long as possible.¹³⁰ Among African American communities, "studies indicate that African-Americans tend to be less comfortable discussing death, more likely to want life-prolonging therapies, and more likely to agree that those who believe in God should not have to plan for end-of-life care than Caucasians."¹³¹

B. THE INSUFFICIENT END-OF-LIFE CARE PROFESSIONAL WORKFORCE

Despite the recent growth of hospice providers and hospice care institutions, an insufficient number of healthcare professionals are entering palliative and comfort care end-of-life care professions to meet Congressional

123. *Id.* at 273, 277.

124. Akah, *supra* note 25, at 77.

125. Perez & Cerminara, *supra* note 30, at 277-78.

126. *Id.* at 277-78.

127. *Id.* at 270.

128. *Id.* at 281.

129. Noah, *supra* note 30, at 360.

130. Perez & Cerminara, *supra* note 30, at 274.

131. *Id.* at 279.

goals of providing cost-effective palliative and compassionate comfort care to dying patients and their families, especially among the increasingly aging population of the United States.¹³² The hospice care movement gained popular and congressional support from the 1960s through the early 1980s as service-based, altruistic program.¹³³ Concerns about the continuation of this model arose shortly after the passage of the Medicare Hospice Benefit in 1982. Indeed, “[a]s early as 1985, [scholars] worried that the ‘smaller, volunteer-oriented hospices, which have contributed significantly to the image of hospice in our country, may be unable to survive in a commercialized environment.’”¹³⁴ Over recent decades, more than 1,000 new hospice providers have entered the American medical establishment.¹³⁵ However, this growth reflects the rise of a business model to hospice care in opposition to its original service model.¹³⁶ For example, the “hospice industry’s enormous growth is attributable to many factors, including ‘compensation based on enrollment numbers, pay to nursing-home doctors who double as hospice medical directors, and gifts to the nursing facilities.’”¹³⁷ These factors have led to fraud within the hospice industry, as for-profit hospice providers try to increase their numbers of patients by inadequately following Medicare rules, such as by over-diagnosing terminal illness to meet the six-month prognosis rule.¹³⁸ When the six-month prognosis rule went into effect, hospice providers primarily treated cancer patients, with relatively predictable disease progressions and prognoses.¹³⁹ Recent increases in terminal illnesses, such as dementia, among elderly Americans has made predictably prognosing death within a six-month window more difficult.¹⁴⁰ This unpredictability of death among many patients has led to some “perverse incentives” among hospice providers, including “cherry-picking of non-cancerous” patients.¹⁴¹ There are concerns about “recruiting” practices among private and for-profit hospice providers, including VITAS Hospice Services, LLC, the largest provider of hospice services in the United States.¹⁴² These practices have led MedPAC (an independent organization created by Congress to advise Congress on issues related to Medicare and Medicare expenditures)¹⁴³ to recommend that the Office of Investigator General (an office

132. See, e.g., Misichko, *supra* note 2, at 432.

133. Perry & Stone, *supra* note 27, at 227.

134. *Id.* at 227.

135. Misichko, *supra* note 2, at 430.

136. *Id.* at 464.

137. *Id.* at 433.

138. *Id.*

139. Hallarman et al., *supra* note 1, at 180-81.

140. Gillick, *supra* note 4, at 31.

141. Ledden, *supra* note 8, at 395, 421.

142. Perry & Stone, *supra* note 27, at 228.

143. Misichko, *supra* note 2, at 428.

established to deter waste, fraud, and abuse by Medicare and other Department of Health and Human Service programs)¹⁴⁴ investigate “financial relationships between hospices and long-term care facilities that may represent a conflict of interest and influence admissions to hospice;...the appropriateness of enrollment practices...; [and] the appropriateness of hospice marketing materials and other admissions practices.”¹⁴⁵ The emphasis on quantity of care rather than quality of care within the hospice industry, leads to higher costs among hospice patients and less individualized care to each patient.¹⁴⁶ Increasing numbers of for-profit hospice providers put shareholders’ economic interest in conflict with the hospice movement’s mission of providing individualized compassionate comfort care to dying patients.¹⁴⁷

In contrast to the recent growth of business-oriented hospice care, non-hospice palliative providers are in short supply, especially in rural and remote areas around the United States. Sase and Eddy report that “[a]cross the United States, there is one palliative care physician for every 1,200 patients with a serious life-threatening illness.”¹⁴⁸ This lack of a workforce in end-of-life care within the American medical system results in regional disparities in access to end-of-life care throughout the country, with remote and rural areas facing severe shortages of availability and accessibility of end-of-life care healthcare professionals.¹⁴⁹ For example, the availability of access to palliative care at medical institutions in Alaska is about twenty-five percent, compared with near one hundred percent availability of access to palliative care at medical institutions in New Hampshire.¹⁵⁰

C. THE LACK OF EDUCATION OF HEALTHCARE PROFESSIONALS IN END-OF-LIFE CARE AND COMMUNICATION

In addition to insufficient numbers of healthcare professionals entering palliative comfort care fields, healthcare professionals in general lack skills, training, and experience in communicating about death and end-of-life care with their patients. Legislative findings assert that “[h]ealth care providers need better education about pain management and palliative care.”¹⁵¹ A 2001 study indicated that “[m]ost new physicians leave medical school and residency programs with little or no training or experience in caring for

144. *Id.* at 429.

145. Perry & Stone, *supra* note 27, at 228.

146. Misichko, *supra* note 2, at 433.

147. *E.g.*, Perry & Stone, *supra* note 27, at 224.

148. Sase & Eddy, *supra* note 3, at 12.

149. *Id.*

150. *Id.*

151. H.R. 1676, 115th Cong. § 2(4) (2017); S. 693, 115th Cong. § 2(4) (2017).

dying patients,” and nurses and social workers with adequate training are also in short supply.¹⁵² Furthermore according to legislative findings, “[s]tudents graduating from medical, nursing and other health professional schools today have very little, if any, training in the core precepts of pain and symptom management, advance care planning, communication skills, and care coordination for patients with serious or life-threatening illness.”¹⁵³ Even specialists lack training, as a 2015 national survey found hematology/oncology fellows “inadequately prepared” to provide palliative care to patients, and twenty-five percent of fellows reported having had no explicit teaching on “key skills,” including assessing prognosis, conducting a family meeting to discuss treatment options, and referral to palliative care, despite Accreditation Council for Graduate Medical Education (ACGME) requirements.¹⁵⁴

The rational, scientific, and technological basis of the modern American medical system has exacerbated healthcare professionals’ inability to communicate with patients and their family members concerning death and end-of-life care, as such “reductionism” has led to the “objectification of the doctor/patient relationship.”¹⁵⁵ Furthermore, scientific and technological advancements in the medical fields have greatly improved medical professionals’ ability to extend and prolong life, leading many in the healthcare professions to view death as a failure and contributing to a “conspiracy of silence” around the topic of patient death and end-of-life care.¹⁵⁶

Such lack of communication by healthcare professionals with patients and family members concerning death and the end of life hinders access to hospice and palliative care because when healthcare professionals fail to initiate conversations about end-of-life care, patients and their families remain uninformed about their options for end-of-life care.¹⁵⁷ Generally, patients make decisions regarding their health care based on the expectation of “complete, honest communication” from their physicians, but “one study found that only two-thirds of doctors told their patients that their illnesses were incurable, and only about a third ever communicated the patient’s true prognosis.”¹⁵⁸ Physicians, in particular, “resist and avoid end-of-life conversations with their patients.”¹⁵⁹ Unfortunately, this resistance harms patients and their families because “when there were no end-of-life conversa-

152. Unroe & Meier, *supra* note 16, at 423.

153. H.R. 1676, 115th Cong. § 2(4) (2017); S. 693, 115th Cong. § 2(4) (2017).

154. *Id.*

155. Walsh, *supra* note 20, at 1122.

156. *Id.* at 1123.

157. Shelley, *supra* note 19, at 585.

158. Lowin, *supra* note 14, at 173.

159. Shelley, *supra* note 19, at 593.

tions, patients and caregivers showed more signs of psychological harm.”¹⁶⁰ This discomfort with discussing end-of-life issues and its accompanying harm to patients is especially problematic in regard to hospice care, as physicians admit they avoid even using the word “hospice” because of its association with death and negative connotations.¹⁶¹ Hospice care is “[i]ntuitively... at odds with the training and mindset of medical professionals. Since leaving medical school, a physician’s end goal is always the same: do everything you can to prolong life. This may make a physician or doctor unable to refer patients to hospice care.”¹⁶² Furthermore, these communication problems extend beyond patient-physician communications, to communication between physicians and patient family members, as health care providers lack expertise, training, and experience in engaging families.¹⁶³ Such communication barriers with families hampers palliative care and hospice care development because of importance of family and caregiver support of this model of care.¹⁶⁴

IV. THE PALLIATIVE CARE AND HOSPICE EDUCATION AND TRAINING ACT (PCHETA)

The Palliative Care and Hospice Education and Training Act (PCHETA) is a bill introduced in the 115th United States Congress, in both the Senate and the House of Representatives, which seeks to address the problems facing the current palliative care and hospice model by “providing palliative medicine training in a variety of settings, including hospice.”¹⁶⁵ According the legislative synopsis, the bill specifically seeks to:

amend the Public Health Service Act to increase the number of permanent faculty in palliative care at accredited allopathic and osteopathic medical schools, nursing schools, social work schools, and other programs, including physician assistant education programs, to promote education and research in palliative care and hospice, and to support the development of faculty careers in academic palliative medicine.¹⁶⁶

160. *Id.*

161. Ledden, *supra* note 8, at 391.

162. Misichko, *supra* note 2, at 452.

163. Ornstein et al., *supra* note 55, at 878.

164. *See id.* at 877-878.

165. NAT’L HOSPICE & PALLIATIVE CARE ORG., *supra* note 18.

166. H.R. 1676, 115th Cong. Synopsis (2017); S. 693, 115th Cong. Synopsis (2017). Palliative Care and Hospice Education and Training Act, H.R. 1676, 115th Cong. Synopsis (2017).

These amendments require the Secretary of Health and Human Services (HHS) to (1) award grants or contracts for the establishment or operation of palliative care and hospice education centers, (2) establish a program of Palliative Medicine and Hospice Academic Career Awards to promote the career development of academic palliative care and hospice physicians, (3) award grants or contracts to Palliative Care and Hospice Education Centers to promote palliative care workforce development, and (4) award grants or contracts to establish a program of Palliative Care and Hospice Career Awards and fellowships to individuals to foster interest among health professionals to enter the field of palliative care.¹⁶⁷ The bill also allows the Secretary to provide grants to health professional education centers to fund the training of physicians who plan to teach palliative medicine.¹⁶⁸ The bill further provides requirements for a National Palliative Care Education and Awareness Campaign as well as research initiatives to be administered by HHS and the National Institutes of Health (NIH).¹⁶⁹ Furthermore, Section Five of the bill requires the National Institutes of Health (NIH) to develop and implement a National Palliative Care Education and Awareness Campaign to inform patients, families, and healthcare professionals about the benefits of palliative care throughout the course of care for serious and life-threatening illness.¹⁷⁰ Importantly, the bill requires the campaign to “target specific populations, including patients with serious or life-threatening illness who are among medically underserved populations . . . and families of such patients or health professionals serving medically underserved populations,” including “racial and ethnic minority populations.”¹⁷¹

The PCHETA bill as introduced in the 115th Congress (2017-18) has wide support and bipartisan sponsorship in both the United States Senate and House of Representatives.¹⁷² This legislative effort is the latest in a series of Congressional efforts to pass federal legislation to promote palliative care and hospice care education and training, which have gained increasing support for over a decade.¹⁷³ This bill evolved from an earlier legislative effort, called the Palliative Care Training Act, first introduced in the 108th Congress in 2004, before hospice and palliative care was formally recognized as a medical subspecialty by the American Board of Medical Subspecialties (ABMS), the Accreditation Council for Graduate Medical

167. *Id.*

168. *Id.*

169. H.R. 1676.

170. *Id.*

171. *Id.*

172. NAT'L HOSPICE & PALLIATIVE CARE ORG., *supra* note 18.

173. Ramthun & Kocinski, *supra* note 5.

Education (ACGME) in 2006, and the Center for Medicare and Medicaid Services (CMS) in 2008.¹⁷⁴

Democratic Senator Ron Wyden of Oregon worked with members of the American Academy of Hospice and Palliative Medicine to draft and introduce this bill in the United States Senate on November 11, 2004.¹⁷⁵ The Palliative Care Training Act sought to increase the number of permanent faculty specializing in palliative medicine at accredited allopathic and osteopathic medical schools and promote the development of faculty careers for academic palliative specialists who emphasize teaching.¹⁷⁶ The bill proposed to accomplish this goal through the establishment of Hospice and Palliative Care Academic Career Awards.¹⁷⁷ Introduced late in the Congressional session, the legislation failed to gain much support, and Senator Wyden reintroduced the bill in the Senate in 2005, early in the 109th Congress.¹⁷⁸

After hospice and palliative care was formally recognized as a medical specialty by ABMS, ACGME, and CMS, Senator Wyden again worked with AAHPM to update and redraft the bill, retitled the Palliative Care and Hospice Education and Training Act (PCHETA).¹⁷⁹ With additional input from many other organizations specializing in hospice and palliative care, including the National Hospice and Palliative Care Organization (NHPCO), the Hospice and Palliative Nurses Association (HPNA), and the American Geriatrics Society (AGS), the newly redrafted bill was modeled after successful geriatric education programs the United States Congress had previously implemented.¹⁸⁰ PCHETA was introduced concurrently in both the United States Senate and House of Representatives on July 19, 2012 during the 112th Congress, in conjunction with AAHPM's annual Capitol Hill Days in Washington, DC.¹⁸¹ It was introduced in the Senate by Senator Wyden and in the House of Representatives by Democratic Representative Eliot Engel of New York, a senior member of the House Energy and Commerce Committee.¹⁸² In the House, the bill was referred to this committee,

174. *Id.*

175. *Id.*

176. Ramthun & Kocinski, *supra* note 5.

177. *Id.*

178. *Id.*

179. *Id.*

180. *Id.*

181. Palliative Care and Hospice Education and Training Act, H.R. 6155, 112th Cong.; S. 3407, 112th Cong. (2012); Ramthun & Kocinski, *supra* note 5.

182. Ramthun & Kocinski, *supra* note 5. (In introducing the bill, Senator Wyden focused on the gap between the need for and access to palliative and hospice care in the United States, stating:

Right now, there are simply not enough well-trained doctors to handle the overwhelming need for specialized treatment coordinated with patients, their families, and across all their

which has jurisdiction over the programs addressed in the bill.¹⁸³ Although introduced late in the Congressional session, the bill gained support from six additional cosponsors in the Senate, and thirty-nine additional cosponsors in the House of Representatives before the close of the session.¹⁸⁴ All of the cosponsors in the Senate were Democrats, while two of the cosponsors in the House of Representatives were Republicans.¹⁸⁵

Senator Wyden and Representative Engel concurrently reintroduced the bill during the 113th Congress on March 23, 2013.¹⁸⁶ Republican Representative from New York, Tom Reed, signed on as the lead Republican cosponsor in the House of Representatives, leading to greater bipartisan support in the House of Representatives.¹⁸⁷ In this session of Congress, PCHETA gained the support of twenty-four cosponsors in the Senate and 170 cosponsors in the House.¹⁸⁸ Again, all of the cosponsors in the Senate were Democrats, while thirty-two cosponsors in the House were Republicans.¹⁸⁹ Prior to the commencement of the 114th Congress, Senator Wyden ascended to chair the Senate Finance Committee.¹⁹⁰ Representative Engel again introduced PCHETA in the House of Representatives during the 114th Congress on July 21, 2015.¹⁹¹ Democratic senator from Wisconsin Tammy Baldwin became the bill's chief sponsor, introducing it on March 5, 2016.¹⁹² The bill had been re-drafted to include provisions for hospice and

healthcare providers...By improving the training in these areas and incentivizing the study and practice of palliative and hospice care, more patients suffering from serious illnesses will be able to have access to care that will improve their quality of life.

Ramthun & Kocinski, *supra* note 5.).

183. Ramthun & Kocinski, *supra* note 5.

184. *Id.*

185. *Id.*

186. Palliative Care and Hospice Education and Training Act, H.R. 1339, 113th Cong.; S. 641, 113th Cong. (2013).

187. Ramthun & Kocinski, *supra* note 5.

188. *Id.*

189. *Id.*

190. *Id.*

191. H.R. 3119, 114th Cong. (2015).

192. S. 2748, 114th Cong. (2016). Upon introducing the bill, Senator Baldwin focused on the support hospice and palliative care professionals bring to patients and their families:

I'm proud to lead the introduction of the Palliative Care and Hospice Education and Training Act to help grow and sustain our healthcare workforce to safeguard and improve the quality of care for the growing number of patients with serious or life threatening illnesses. . . . This issue is especially personal to me, as I was raised by my maternal grandparents and later served as my grandmother's primary caretaker as she grew older. I know firsthand the importance of ensuring that there are enough trained healthcare professionals to provide quality care across

palliative care nurse education, practice, and quality grants; workforce development; and nurse retention projects; as well as provisions to conduct national education and awareness campaigns on hospice and palliative care.¹⁹³ In the 115th Congress, the bill gained wide support in the House of Representatives, gaining co-sponsorship from 234 sponsors.¹⁹⁴ It was sponsored by more than half of all representatives.¹⁹⁵ Due in part to its change in sponsorship and later introduction in the Senate, the numerical gains in co-sponsorship were more modest, with twenty senators signing on as co-sponsors.¹⁹⁶ Importantly, however, Republican senator from West Virginia Shelley Moore Capito offered her support as a co-sponsor shortly after the bill's introduction in the Senate, ensuring bipartisan support for the bill in both houses of Congress.¹⁹⁷

On March 22, 2017, Senator Baldwin and Representative Engel again jointly introduced PCHETA in the United States Senate and House of Representatives.¹⁹⁸ Senator Capito joined Senator Baldwin as an original co-sponsor in the Senate, and Representatives Tom Reed and Earl L. Carter, both Republicans, joined Representative Engel as original co-sponsors in the House.¹⁹⁹ As of February 2018, the bill gained much bipartisan support in both chambers of Congress, with twenty-nine co-sponsors in the Senate, including fifteen Republicans, and 251 co-sponsors in the House of Representatives, including ninety-eight Republicans.²⁰⁰

the country and to fulfill the needs and wishes of patients and their families.

Ramthun & Kocinski, *supra* note 5.

193. Ramthun & Kocinski, *supra* note 5.

194. *Id.*

195. *Id.*

196. *Id.*

197. *Id.*

198. H.R. 1676, 115th Cong. (2017); S. 693, 115th Cong. (2017).

199. *Id.*

200. *Id.* In explaining her support for the bill, Senator Deb Fisher, Republican from Nebraska, focused on the bipartisan support of the bill and the comfort an adequate hospice and palliative care workforce can provide to patients and family members:

Watching a loved one struggle with a serious illness or face the final stages of life is devastating and stressful. I am...backing bipartisan legislation called the Palliative Care and Hospice Education Act (PCHETA). This act aims to provide comfort to patients and their families facing illnesses like cancer or Alzheimer's. Through increased education, training, and incentives for physicians providing this type of care, Americans can receive better care during these very difficult circumstances.

Deb Fisher, *Hope and Comfort*, YORK NEWS TIMES (October 26, 2017), http://www.yorknewstimes.com/editorial/hope-and-comfort/article_367638cc-b9d3-11e7-85bb-4bedd4c1cbfc.html?utm_medium=social&utm_source=email&utm_campaign=user-share [https://perma.cc/FNP9-K8K4].

In addition to the wide support among federal legislators, PCHETA also has gained the support of many organizations specializing in hospice and palliative care and other healthcare issues facing older and aging Americans. The Patient Quality of Life Coalition (PQLC), a network of stakeholder organizations formed to advocate for the interests of patients and families facing serious illness, supports PCHETA.²⁰¹ More than fifty non-profit and nongovernmental organizations signed and submitted letters in support of PCHETA.²⁰² In addition to signing on to these letters, the Alzheimer's Association and Alzheimer's Impact Movement (AIM) submitted a joint separate letter of support for PCHETA.²⁰³ The Association of Oncology Social Work (AOSW) further supports PCHETA because it would "help to ensure an adequate, appropriately trained healthcare workforce to provide [hospice and palliative care] services."²⁰⁴ In its own letter of support of PCHETA, the National Hospice and Palliative Care Organization "strongly supports this effort and encourages its prompt consideration and passage,"²⁰⁵ asserting that the legislation "will ensure that a sufficient number of well-trained palliative professionals is available to care for individuals with serious illness at the end of life."²⁰⁶

V. RECOMMENDATIONS AND CONCLUSION

The Palliative Care and Hospice Education and Training Act (PCHETA) has evolved into a comprehensive piece of legislation, which addresses the lack of racial and ethnic minority utilization of hospice and palliative care, the lack of a professional healthcare workforce specialized in hospice and palliative care, and the inadequacy of communication skills in discussing serious and life-threatening illness and end-of-life issues

201. Elizabeth Franklin, *Palliative Care and Hospice Education and Training Act (PCHETA)*, AOSW ACTION NETWORK (Feb. 9, 2017), <https://www.aosw.org/aosw-action-network/february-2017/palliative-care-and-hospice-education-and-training/> [<https://perma.cc/U7KR-CJUJ>].

202. Letter from Acad. of Integrative Pain Mgmt. et al. to Tammy Baldwin & Shelley Moore Capito (Mar. 23, 2017), http://polst.org/wp-content/uploads/2017/03/PCHETA-Senate-Support-Letter-115th-Congress_03.23.2017.pdf [<https://perma.cc/B22K-JKBT>].

203. Press Release, Alzheimer's Ass'n, *Palliative Care and Hospice Education and Training Act (PCHETA) Introduced in Congress* (Mar. 22, 2017), https://alzimpact.org/press/press_release/id/75 [<https://perma.cc/DSC3-78XG>]. (Statement of Alzheimer's Association chief public policy officer and AIM Executive Director). (Palliative and hospice care are important services for people living with Alzheimer's and other dementia. The availability of palliative and hospice care is growing, but the need is growing faster—and the quality of the care remains a concern. This legislation would increase the availability and quality of care).

204. Franklin, *supra* note 201.

205. Banach, *supra* note 65, at 2.

206. *Id.* at 1.

among healthcare professionals. However, specific language should be added to the bill to ensure the promotion of communication skills in discussing serious and life-threatening illness and end-of-life issues. Further, the bill's provisions regarding the promotion of hospice and palliative care utilization among racial and ethnic minorities should be clarified.

If enacted, PCHETA is particularly effective at promoting the development of a more robust professional healthcare workforce in hospice and palliative care.²⁰⁷ The bill provides numerous incentives for healthcare educational institutions, individual healthcare academic faculty, and individual healthcare professionals and students to invest in hospice and palliative care education and training. It provides requirements for grants for Palliative Care and Hospice Education Centers for healthcare educational and training institutions.²⁰⁸ For healthcare academic faculty, it provides for Palliative Medicine and Hospice Academic Career Awards.²⁰⁹ For healthcare professionals and students, it provides Palliative and Hospice Career Incentive Awards and institutional fellowships to pursue hospice and palliative care education and training.²¹⁰ These provisions offer both financial incentives in the form of monetary grants and professional prestige in the form of receipt of competitive awards, and they are likely to effectively motivate healthcare institutions, professionals, and students to invest in hospice and palliative care training because money and prestige are widely accepted as strong motivators of personal and professional behavior.²¹¹ Thus, the bill largely accomplishes the goal of developing a more robust workforce in hospice and palliative care, and these provisions should be fully supported.

Furthermore, the PCHETA addresses the problem of inadequate communication skills among healthcare professionals concerning serious and life-threatening illness.²¹² The incentivized palliative and hospice care education and training programs would likely include end-of-life care communication as part of a palliative and hospice care skill set and philosophy.²¹³ However, the bill does not directly provide for any required end-of-life care

207. See discussion *infra* Part III(C) for a discussion of this problem with the palliative and hospice care model in the United States.

208. H.R. 1676, 115th Cong. (2017); S. 693, 115th Cong. (2017).

209. *Id.*

210. *Id.*

211. See, e.g., Nadja Damij et al., *What Motivates Us for Work? An Intricate Web of Factors beyond Money and Prestige*, PLOS ONE (July 15, 2015), <http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0132641> [<https://perma.cc/XPP7-95PM>] (“[M]ost ‘traditional’ motivation theories emphasize money (individual economic benefit) and prestige (honour, recognition in society) as the only true widely applicable motivators, at least in the Western societies.”).

212. See discussion *infra* Part III(B) for a discussion of this problem with the palliative and hospice care model in the United States.

213. See generally Cerminara, *supra* note 20.

communication education or training tied to any of its funding provisions, so such education and training is not guaranteed by the text of the bill. The bill should be amended to add language requiring the teaching of end-of-life communication skills, including discussing serious and terminal illness, to ensure that this important need is addressed.

Finally, the PCHETA proposes an important step in addressing the lack of racial and ethnic minority utilization of hospice and palliative care with its requirement of a National Palliative Care Awareness Campaign targeting medically underserved populations, including racial and ethnic minority populations.²¹⁴ Public information and awareness campaigns are often effective tools for achieving public policy goals when the target population and the process for disseminating the information to the population are all clearly defined.²¹⁵ The PCHETA defines a “medically underserved” target population and provides minimal guidelines for determining the relationship between this target population and the public policy goal of increasing awareness and utilization of hospice and palliative care among this target population.²¹⁶ It also provides minimal guidance for the process of disseminating information to this population.²¹⁷ However, additional language should be amended to the bill, clarifying these terms and objectives, to facilitate the public policy goal of promoting hospice and palliative care utilization among racial and ethnic minority populations.

The PCHETA defines a target population for the National Palliative Care Awareness Campaign by mandating that the National Institutes of Health (NIH) “target specific populations, including patients with serious or life-threatening illness who are among medically underserved populations [as defined by the Public Health Service Act]²¹⁸ and families of such patients or health professionals serving medically underserved populations.”²¹⁹ It further provides a specific list of populations NIH is required to target for purposes of the National Palliative Care Awareness Campaign, including “racial and ethnic minority populations.”²²⁰ This specific inclusion of racial and ethnic minorities in the plain language of the bill is an important step in furthering their awareness and utilization of hospice and palliative care. Furthermore, the inclusion of families and health profes-

214. H.R. 1676, 115th Cong. (2017); S. 693, 115th Cong. (2017).

215. Janet A. Weiss & Mary Tschirhart, *Public Information Campaigns as Policy Instruments*, 13 J. POL’Y ANALYSIS & MGMT 82, 106 (1994).

216. H.R. 1676, 115th Cong. (2017); S. 693, 115th Cong. (2017).

217. *Id.*

218. 42 U.S.C.S. § 254b(3)(A) (LEXIS through Pub. L. No. 115-117) (“The term ‘medically underserved population’ means the population of an urban or rural area designated by the Secretary as an area with a shortage of personal health services or a population group designated by the Secretary as having a shortage of such services.”).

219. H.R. 1676, 115th Cong. (2017); S. 693, 115th Cong. (2017).

220. H.R. 1676, 115th Cong. (2017); S. 693, 115th Cong. (2017).

sionals serving racial and ethnic minority patients and minority patients' families will likely lead to greater awareness and discussion of hospice and palliative care among minority patients because the people with whom they are most likely to discuss healthcare problems and decisions will be better informed. However, while the bill lists racial and ethnic minority populations, it provides no guidance on defining this term. Language should be amended to the bill to describe a process for defining and determining racial and ethnic minority populations to ensure that the intended populations are targeted to facilitate the public policy goal of promoting hospice and palliative care utilization among minority populations.

Furthermore, the PCHETA offers minimal guidance for defining the relationship between the racial and ethnic minority target population and the public policy goal of increasing awareness and utilization of hospice and palliative care among this target population, and it offers minimal guidance for the process of disseminating this information to this target population. It mandates NIH to "consult with appropriate professional societies, hospice and palliative care stakeholders, and relevant patient advocacy organizations" in planning and implementing the National Palliative Care Awareness Campaign.²²¹ This mandate importantly grants administrative discretion to NIH to develop appropriate rules and regulations for the campaign while also requiring the input of important and relevant interest groups. However, it should more clearly define the relationship between the racial and ethnic minority target population and the public policy goal of increasing awareness and utilization of hospice and palliative care by establishing specific benchmarks for the campaign. For example, it should require the campaign to actively disseminate information in a specified number of racial and ethnic minority communities by a specified date. Furthermore, it should provide specific methods of measuring the success of the campaign by establishing methods of tracking and documenting hospice and palliative care utilization among the target group. It should further establish goals of increasing this utilization by a certain percentage of the populations of these communities by a specified date. Administrative discretion should be left to NIH, with consultations with relevant interest groups, to establish rules and regulations to meet these benchmarks and goals.

Also, the PCHETA should provide specific guidelines for establishing a process of disseminating information for the campaign. These guidelines should specify minimum requirements for information to be included in the campaign and methods for disseminating it. For example, they should require the campaign to include information about the health, social, and cost benefits of hospice and palliative care. They should further require that the

221. H.R. 1676, 115th Cong. (2017); S. 693, 115th Cong. (2017).

information be disseminated through appropriate methods including print brochures and posters, television and radio commercials, internet banners, and social media posts. Administrative discretion should be left to NIH, with the consultation of relevant interest groups, to establish rules and regulations to develop this specified process. These minimal benchmarks, goals, and requirements ensure that the campaign will pursue the public policy goal of promoting hospice and palliative care utilization among racial and ethnic minority populations while still allowing appropriate administrative discretion to NIH with input from relevant interest groups.

Ultimately, the PCHETA represents a major step in improving palliative and hospice care and access to this model of medical care in the United States because it strongly supports further development of a professional healthcare workforce dedicated to providing appropriate care for individuals with serious and life-threatening illnesses and providing support for their families. However, further steps will need to be taken to directly address the lack of communication skills among healthcare professionals and patients and their families regarding serious and life-threatening illnesses and end-of-life issues and the lack of access to hospice care by racial, ethnic, and religious minorities.