

**A NUDGE IN THE RIGHT DIRECTION WITH A STICK THE SIZE
OF CMS: PHYSICIAN-PATIENT COMMUNICATION
AT THE END OF LIFE**

Mom, you are the best mom, and I love you. It's OK for you to go because I don't want you to be in pain.

-Aubrey (Michelle Hargett-Beebee's daughter moments after Michelle died)¹

I. INTRODUCTION

By 2030, 20% of the United States population will be 65 or older.² But death, dying, and chronic conditions are not just the purview of the old. Michelle Hargett-Beebee was just 43, a young mother, when she died of cancer in her home.³ Sons, daughters, mothers, fathers, and even siblings are more and more being called into the role of caregiver, their lives drastically affected by the dying process.⁴

Palliative care, especially at the end of life, benefits both patients and their caregivers as they struggle with the difficult decisions brought on by chronic disease and terminal illness.⁵ Unfortunately, too few individuals are receiving appropriate palliative care.⁶ One key reason is that reimbursement methods have created perverse incentives for physicians and other professionals resulting in an arguable decline in quality of care and barriers to entry for patients.⁷ Additionally, effective patient-physician communication, vital to appropriate end-of-life care, rarely occurs.⁸

1. Bruce Newman, *Life in a Year: Saying Goodbye to the Cycle of Life*, SAN JOSE MERCURY NEWS (Dec. 25, 2009, 3:58 PM), http://www.mercurynews.com/life-in-a-year/ci_14070282?nclick_check=1.

2. R. Sean Morrison & Diane E. Meier, *Palliative Care*, 350 NEW ENG. J. MED. 2582, 2582 (2004).

3. Newman, *supra* note 1.

4. See, e.g., NAT'L ALLIANCE FOR CAREGIVING & AM. ASS'N OF RETIRED PERSONS, *CAREGIVING IN THE U.S. 2009*, at 4 (2009) (finding that about 29% of respondents or approximately 66 million people in the U.S. serve as caregivers).

5. See *infra* Part II.

6. See *infra* Part II.

7. See *infra* Part II. By "barriers of entry," I mean both the for-profit tendency to cherry-pick non-cancerous patients and those with dementia, the resulting long hospice length of stay (LOS), and physician fears that foster very short stays in hospice.

8. See *infra* Part II.B.2.

Advances in medical technology mean little if patients are left unaware of their benefits.⁹ The lack of satisfactory pain management is an especially disturbing area of this physician-patient disconnect.¹⁰ Individuals, such as members of Michelle Hargett-Beebee's family,¹¹ report seeing their loved ones dying in pain.¹²

Two states, California and New York, have passed legislation,¹³ and others have considered legislation,¹⁴ creating either an active or conditional legal duty on the part of a physician to inform terminal patients or their caregivers of their rights at the end of life, including pain management. The statutes have different enforcement mechanisms. The California law supports a claim for reckless neglect under the state's Elder and Dependent Adult Abuse statute.¹⁵ The more recent New York statute, as an act under the state's Public Health Law, provides for fines and criminal penalties.¹⁶ However, potential problems exist at the state level. New York and California have different triggers to the physician's duty,¹⁷ varied approaches to elder abuse,¹⁸ and the California elder abuse statute has not yet been proven to protect all patients, just a specific class.¹⁹ Instead, Medicare's Conditions of Participation²⁰ should require hospitals to provide terminally ill patients and their families with information about the end of life.²¹

Part II of this article describes the essential who, what, where, and how of palliative care and hospice, paying special attention to the rise of big business hospice and cost-of-care under Medicare.²² This section will also

9. See *infra* Part II.B.2.

10. See *infra* Part II.B.3.

11. Amended Complaint at 14, 17, 19, *Hargett v. Vitas*, No. RG10547255 (Cal. Super. July 6, 2011).

12. See *infra* Part III.A.1.

13. Right to Know End of Life Options Act, CAL. HEALTH & SAFETY CODE § 442.5 (West 2010); N.Y. PUB. HEALTH LAW § 2997-c (McKinney 2011).

14. See, e.g., H. 274, 2011-2012 Leg. Sess., (Vt. 2011); see e.g., S.B. 1311, 49th Leg., 1st Reg. Sess. (Az. 2009).

15. CAL. HEALTH & SAFETY CODE § 442.5.

16. N.Y. PUB. HEALTH LAW § 2997-c.

17. CAL. HEALTH & SAFETY CODE § 442.5; N.Y. PUB. HEALTH LAW § 2997-c.

18. California addresses elder abuse civilly. Elder Abuse and Dependent Adult Civil Protection Act, CAL. WELF. & INST. CODE §§ 15600-15675 (West 2012). New York approaches elder abuse criminally. NY PENAL LAW § 120.05(12) (McKinney 2010).

19. CAL. WELF. & INST. CODE §§ 15600-15675.

20. Medicare Conditions of Participation (COPs) are standards that a healthcare facility must meet in order to be eligible for Medicare reimbursement. See BARRY R. FURROW ET AL., HEALTH LAW 547-48 (2d ed. 2000).

21. See *infra* Part IV.

22. See *infra* Part II.A-B.

examine end-of-life communication breakdowns and inadequate pain management, all of which contribute to the broken promise of palliative care.²³ Part III looks at how California and New York have approached these failures with differing state statutes and evaluates each of their shortcomings.²⁴ Part IV suggests that a national standard in the form of Medicare Conditions of Participation be adopted.²⁵

II. PALLIATIVE CARE AT THE END OF LIFE (SHHH. . . THAT'S H-O-S-P-I-C-E)

The term "hospice" has become a dirty little word. Physicians admit they avoid the phrase because of its negative connotations.²⁶ Like a plague, it causes them to run. Instead they suggest "palliative care" for the patient.²⁷ "Palliative care" does have a more benevolent tone.²⁸ It sounds caring.²⁹ Palliative care, from the Latin *pallium*, or cloak, offers patients symptom management and comfort, parallel to their curative treatment regimen.³⁰ However, palliative care when someone is terminally ill is *H-O-S-P-I-C-E*.³¹

In an already emotional time, confusion about hospice and palliative care further muddies the waters. Therefore, this section first clarifies the field of "palliative care."³² Then it defines and illuminates hospice explaining how hospice improves both patient and caregiver quality of life and reduces healthcare costs.³³ Finally, the section concludes with how the promise of palliative care has been broken by a perverse reimbursement system, poor physician-patient communication, and inadequate pain management.³⁴

A. *The Promise of Palliative Care*

"Palliative care is not just for the imminently dying . . ."³⁵ This common misconception often keeps patients from pursuing treatment.³⁶

23. See *infra* Part II.B.

24. See *infra* Part III.

25. See *infra* Part IV.

26. William M. Lamers, Jr., *Defining Hospice and Palliative Care: Some Further Thoughts*, 16 J. PAIN & PALLIATIVE CARE PHARMACOTHERAPY 65, 67 (2002).

27. *Id.*

28. *Id.*

29. See *id.*

30. MERRIAM-WEBSTER'S COLLEGIATE DICTIONARY 893 (2009); Lamers, *supra* note 26, at 68.

31. See Kathy L. Cerminara, *Hospice and Health Care Reform: Improving Care at the End of Life*, 17 WIDENER L. REV. 443, 445 (2011).

32. See *infra* Part II.A.

33. See *infra* Part II.A.

34. See *infra* Part II.B.

35. J. Andrew Billings, *What is Palliative Care?*, 1 J. PALLIATIVE MED. 73, 77 (1998).

Unfortunately, the definition of palliative care can be confusing, not just for patients, but also for academics.³⁷ The World Health Organization defines palliative care as, “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.”³⁸ Several explanatory notes including one saying palliative care “provides relief from pain and other distressing symptoms” then follow this definition.³⁹ Other scholars define palliative care as “specialized healthcare for anyone who is diagnosed with a serious and life-threatening illness, starting when they get the diagnosis, regardless of the prognosis.”⁴⁰ A “disease . . . not responsive to curative treatment”⁴¹ or an illness “regardless of the prognosis”⁴² includes not only terminal illnesses but also chronic conditions such as heart disease, stroke, or chronic respiratory illnesses.⁴³

On a practical level, palliative care programs offer assistance with assessment and treatment of symptoms (including pain), support for decision-making, a fluid continuum of care, and aid to caregivers.⁴⁴ A palliative care team is multidisciplinary and includes nurses, other medical professionals, and social workers.⁴⁵ This team seeks to be involved in a patient’s life from the day of terminal diagnosis, or longer in the case of chronic illness.⁴⁶ More than 80% of all large hospitals have such a program.⁴⁷

Similarly confusing is what *hospice* is and where it fits into this conversation. Hospice, a subset of palliative care, focuses the efforts

36. R. SEAN MORRISON, SYRACUSE UNIV. MAXWELL SCH. OF CITIZENSHIP & PUB. AFFAIRS, CTR FOR POLICY RESEARCH, POLICY BRIEF NO. 43/2010, PALLIATIVE CARE: A NOVEL SOLUTION TO THE HEALTHCARE CRISIS 1 (2010).

37. See Billings, *supra* note 35, at 73-74 (analyzing several different palliative care definitions and their impact on a potential patient).

38. WHO *Definition of Palliative Care*, WORLD HEALTH ORG. (2013), <http://www.who.int/cancer/palliative/definition/en/>.

39. *Id.*

40. MORRISON, *supra* note 36, at 1.

41. Billings, *supra* note 35, at 74.

42. MORRISON, *supra* note 36, at 1.

43. *Chronic Diseases*, WORLD HEALTH ORG. (2013), http://www.who.int/topics/chronic_diseases/en/.

44. Amy S. Kelley & Diane E. Meier, Editorial, *Palliative Care—A Shifting Paradigm*, 363 NEW ENG. J. MED. 781, 781 (2010).

45. *Id.*

46. Billings, *supra* note 35, at 77.

47. Kelley & Meier, *supra* note 44, at 781.

outlined above on end-of-life care.⁴⁸ From the Latin, *hospes*, meaning guest, hospice was originally provided in a facility.⁴⁹ However, hospice currently refers to program of palliative care at the end of life provided in a multitude of settings, including the home.⁵⁰ Legally, according to the Medicare hospice regulation, the term hospice means “a public agency or private organization or subdivision of either of these that is primarily engaged in providing hospice care” to terminally ill individuals.⁵¹

Many Americans depend on hospice. Almost half of all deaths in the United States occur in a hospice program.⁵² Hospice patients are predominantly white,⁵³ mostly female,⁵⁴ and overwhelmingly old.⁵⁵ That means more than 1.5 million people depend on hospice care in this country every year.⁵⁶ Cancer for many years was the leading cause of hospice admission; now individuals in hospice are more likely to have dementia, heart disease, or lung disease.⁵⁷ However, time in hospice can be short⁵⁸ with most patients using hospice only in their last weeks of life.⁵⁹

The value of palliative care, especially at the end of life, cannot be understated. Palliative care has been shown to increase quality of life for patients and caregivers, reduce healthcare costs, and help patients and families negotiate the healthcare system.⁶⁰ The most surprising finding is that palliative care may actually extend the lives of terminally ill patients.⁶¹ For example, a recent study of lung cancer patients found that patients who

48. See Cerminara, *supra* note 31, at 445-46.

49. WILLIAM CHAMBERS, ETYMOLOGICAL ENGLISH DICTIONARY 299 (A.M. MacDonald ed., 1961); Lamers, *supra* note 26, at 68.

50. Lamers, *supra* note 26, at 69.

51. 42 C.F.R. § 418.3 (2011).

52. NAT'L HOSPICE & PALLIATIVE CARE ORG., NHPCO FACTS AND FIGURES: HOSPICE CARE IN AMERICA 4 (2010). MedPAC reports similarly at 42% of all Medicare decedents. MEDICARE PAYMENT ADVISORY COMM'N, REPORT TO THE CONGRESS: MEDICARE PAYMENT POLICY 265 (2011), available at http://medpac.gov/documents/Mar11_EntireReport.pdf.

53. NAT'L HOSPICE & PALLIATIVE CARE ORG., *supra* note 52, at 7 (80.5% of all Medicare hospice beneficiaries are white).

54. *Id.* at 6. (In 2009, 53.8% of all hospice patients were female).

55. *Id.* (83% of hospice patients are 65 plus with 38% reaching 85 or older. Individuals under the age of 34 account for just 0.8% of all hospice patients).

56. *Id.* at 4.

57. *Id.* at 7. (The top four reasons: “debility unspecified (13.1%), heart disease (11.5%), dementia (11.2%), and lung disease (8.2%).”).

58. NAT'L HOSPICE & PALLIATIVE CARE ORG., *supra* note 52, at 5 (In 2009, the median length of stay was 21.1 days and the mean was 69.0 days. Although this appears to be long, the numbers are declining with the proportion of individuals staying more than 180 days decreasing from 12.1% in 2008 to 11.8% in 2009, a continuation of a several year trend).

59. Billings, *supra* note 35, at 77.

60. See MORRISON, *supra* note 36, at 1.

61. NAT'L HOSPICE & PALLIATIVE CARE ORG., *supra* note 52, at 5.

entered palliative care early lived, on average, an additional two months.⁶² Further, these patients experienced “clinically meaningful improvements in quality of life and mood.”⁶³

Not only patients but also families are affected by the decision to use a palliative care program. Up to 34 million households are impacted at any one time, each with at least one person spending on average 21 hours per week in the caregiver role.⁶⁴ Caregiver quality of life improves when the patient elects palliative care.⁶⁵ For example, Christakis and Iwashyna found that among individuals whose terminally ill spouse chose end-of-life palliation, fewer died within 18 months of the patient’s death.⁶⁶ They suggest that even a short hospice stay, as brief as 3-4 weeks, may have a positive effect on the health status of the patient’s spouse.⁶⁷

Patients who enter palliative care programs at the end of their lives also cost less to care for. Terminal patients, such as those with cancer, tend to use more aggressive and costly treatments.⁶⁸ Temel et al. suggest that entry into palliative care may reduce this societal and personal cost.⁶⁹ Others claim that this is an oversimplification, noting that even when physicians know a patient’s needs, the patient tends to receive unwanted and expensive care.⁷⁰ Instead, these critics argue that such cost savings can be attributed to the change in trajectory that a palliative care consultation creates in a systematic, “avert death at all costs” hospital environment.⁷¹

Sadly, despite the promise of palliative care programs, evidence reveals that these programs are underused. Instead, patient distress, caregiver dissatisfaction, and overuse of costly and ineffective treatments are the norm.⁷²

62. Jennifer S. Temel et al., *Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer*, 363 *NEW ENG. J. MED.* 733, 739 (2010). Temel et al. found that 54% of standard care patients and 34% of early palliative care patients received aggressive care. *Id.* at 738. Aggressive care was defined as either: chemotherapy within fourteen days before death, no hospice care, or admission to hospice three days or less before death. *Id.* at 735.

63. *Id.* at 739.

64. MORRISON, *supra* note 36, at 3.

65. See Nicholas A. Christakis & Theodore J. Iwashyna, *The Health Impact of Health Care on Families: A Matched Cohort Study of Hospice Use by Decedents and Mortality Outcomes in Surviving, Widowed Spouses*, 57 *SOC. SCI. & MED.* 465, 472 (2003).

66. *Id.* at 470.

67. *Id.* at 471.

68. Temel et al., *supra* note 62, at 740.

69. *Id.*

70. R. Sean Morrison et al., *Cost Savings Associated with US Hospital Palliative Care Consultation Programs*, 168 *ARCHIVES INTERNAL MED.* 1783, 1788 (2008).

71. *Id.*

72. Kelley & Meier, *supra* note 44, at 781; MORRISON, *supra* note 36, at 2-4.

B. *The Broken Promise: Misaligned Incentives, Physician-Patient Communication Breakdown, and Inadequate Pain Management*

Palliative care can be a comfort for many.⁷³ When it goes wrong, however, it is so much more than the simple misapplication of a program of care for the patients and caregivers involved. It can be horribly traumatizing to both. Imagine learning only days before your death that you had been terminally ill for much longer. You are stuck in a sterile hospital. Your family has been camped out at the ward instead of at home. When someone tells you, they fumble over the words or follow a script. They may even ask your family for your bed. You might be in pain, terrible pain.

Death is a very personal experience. Unfortunately, medical professionals are failing at providing comfort during a patient's end of life.⁷⁴ It is not all their fault. Medicare has created some perverse incentives that encourage the rise of for-profit hospice of questionable quality and either very long stays or very short stays.⁷⁵ Without proper education about end-of-life communication, fear and apprehension control these interactions, especially in the realm of pain management.

This section will first examine the incentives of the Medicare hospice benefit.⁷⁶ It will then discuss the breakdown in physician-patient communication at the end of life.⁷⁷ Finally, this section will address the importance of adequate pain management.⁷⁸

1. Misaligned Incentives: The Medicare Hospice Benefit

Palliative care treatment can be received concurrently with curative treatment.⁷⁹ Payment for such treatment is treated like any other specialty until it crosses the line to become hospice, or end-stage palliative care.⁸⁰ Medical insurance companies and public payers (such as Medicare and Medicaid) reimburse for consultations, medication, and support services

73. See, e.g., Anemona Hartocollis, *Hard Choice for Comfortable Death: Sedation*, N.Y. TIMES (Dec. 27, 2009), <http://www.nytimes.com/2009/12/27/health/27sedation.html?pagewanted=all>.

74. See *infra* Part II.B.1-2.

75. Both have a negative impact. In the case of short stays, patients are not receiving the benefits of palliative care, as described in Part II.A, for, perhaps, as long as they could or would choose. Patients with very long hospice stays cost Medicare much more money. See *infra* Part II.B.1.

76. See *infra* Part II.B.1.

77. See *infra* Part II.B.2.

78. See *infra* Part II.B.3.

79. See *supra* Part II.A.

80. See, e.g., Charles F. Von Gunten et al., *Coding and Reimbursement Mechanisms for Physician Services in Hospice and Palliative Care*, 3 J. PALLIATIVE MED. 157, 158 (2000) (detailing the ways in which physicians are paid for both hospice and palliative care services).

dependent on their multitude of rules.⁸¹ How Medicare reimburses for palliative care treatment becomes important because of its enormous influence on both insurers and providers.⁸² The in-patient provision of palliative care is paid for under Medicare Part A.⁸³ Medicare pays hospitals a Diagnosis-Related Group (DRG) payment, essentially a flat fee, for each episode of patient care.⁸⁴ Physicians who provide palliative care services are paid under Part B.⁸⁵ Some physicians, specifically many hospitalists, are employed by hospitals and receive a salary or a salary with production bonuses.⁸⁶

The DRG system was established to incentivize reductions in hospital costs.⁸⁷ If a hospital provides care to a patient at costs below the DRG payment, then it gets to keep the difference.⁸⁸ Traditionally, hospitals have failed to see the promise of palliative care, especially for cutting costs.⁸⁹ The old care paradigm was one where curative treatment was provided, without thought to palliative care consultation, until the last six months of life when the Medicare hospice benefit kicked into effect.⁹⁰ More and more, hospitals are moving away from this old model to a new one where palliative care is

81. See, e.g., Steffie Woolhandler et al., *Costs of Health Care Administration in the United States and Canada*, 349 *NEW ENG. J. MED.* 768, 769 (2003) (comparing the healthcare administration costs between the U.S. and Canada). "Fragmentation also raises costs for providers who must deal with multiple insurance products – at least 755 in Seattle alone – forcing them to determine applicants' eligibility and to keep track of the various copayments, referral networks, and approval requirements." *Id.* at 773.

82. Although limited in its scope by eligibility requirements, Medicare pays a large proportion of medical costs given its target population. FURROW ET AL., *supra* note 20, at 538.

83. As mentioned above, palliative care teams usually include nurses, social workers, and medical professionals. See *supra* Part II.A. Nurses and social workers are employed by the hospital and their services are paid under Medicare. 42 C.F.R. § 409.10(a)(2) (2011) (expanded upon in 42 C.F.R. § 409.12 (2011)). As for medical professionals, see *infra* note 86.

84. 42 C.F.R. § 412.2(a) (2011) (defining the prospective payment system); 42 C.F.R. § 412.4(c)-(d) (2011) (explaining DRGs and defining "postacute care transfers").

85. Participating physicians are paid by multiplying the Relative Value Unit (RVU) by the Geographic Adjustment Factor (GAF) by the Conversion Factor (CF). 42 C.F.R. § 414.20 (2011). Medicare then pays the physician the lesser of this value (the fee schedule amount) or her actual charge. 42 C.F.R. § 414.21 (2011). RVUs are established by CMS for a physician's work. 42 C.F.R. § 414.22 (2011).

86. Joseph Ming Wah Li, *Society of Hospital Medicine (SHM) 2007-2008 Productivity and Compensation Survey*, MEDSCAPE INTERNAL MED. (July 29, 2008), <http://www.medscape.org/viewarticle/578134>. In 2008, 40% of hospitalists were employed by hospitals and 24% were employed by academic institutions. *Id.*

87. FURROW ET AL., *supra* note 20, at 552.

88. See *id.*

89. See generally Morrison et al., *supra* note 70 (comparing costs per admission between palliative and "usual care" patients).

90. MORRISON, *supra* note 36, at 9 fig.2.

provided throughout the course of treatment for a chronic or life-threatening illness,⁹¹ perhaps recognizing not just its benefit for patients but also, their bottom line.⁹²

Once a patient qualifies for hospice care, their treatment is no longer paid for under the DRG system.⁹³ Payment for hospice differs from that of palliative care because Medicare has some strict requirements for qualification.⁹⁴ To be eligible to receive Medicare hospice benefits a patient must have only six months left to live, as determined by a physician, and must abandon curative treatment.⁹⁵ Medicare has covered hospice since 1982.⁹⁶ Since then, it has become the primary source of payment for hospice services⁹⁷ and covers the most patient days in hospice.⁹⁸

In addition to reinforcing an outdated treatment model, the Medicare hospice benefit, as the dominant payer in the market, has led to misaligned incentives. The Medicare benefit has been shown to “scare off” physicians and patients at the end of life, resulting in shorter stays generally. The exacting requirements of Medicare have led hospice providers to be cautious in admission and reevaluation of patients.⁹⁹ Hospice has become a place for the imminently dying.¹⁰⁰ Even though patient days increased from 54 to 86 days between 2000 and 2009, this change reflects an increase in the number of long stays, not the median length of stay.¹⁰¹ In fact, the

91. *Id.*

92. Diane E. Meier, *The Development, Status, and Future of Palliative Care*, in *PALLIATIVE CARE: TRANSFORMING THE CARE OF SERIOUS ILLNESS* 3, 54 (eds. Diane E. Meier et al., 2010).

93. 42 C.F.R. § 418.302 (2011).

94. Billings, *supra* note 35, at 76.

95. *Id.* Note that hospice programs are required to certify and recertify at the 60 and 90 day marks. Stephen R. Connor, *U.S. Hospice Benefits*, 38 J. PAIN & SYMPTOM MGMT. 105, 105 (2009). For an overview of the hospice benefit see David E. Thiess, *The Medicare Hospice Benefit After Health Reform: Cost Controls, Expanded Access, and System-Induced Pressures*, 3 J. HEALTH & LIFE SCI. L. 39, 43-46 (2010).

96. Tax Equity and Fiscal Responsibility Act of 1982, Pub. L. 97-248, § 121, 96 Stat. 324, 356 (1982) (codified as amended at 42 U.S.C. 1395d (2012)). Although the act had a 1986 sunset provision, that year Congress made the program permanent. *Id.*

97. NAT'L HOSPICE & PALLIATIVE CARE ORG., *supra* note 52, at 10 (83.4% of hospice patients are covered by Medicare). MedPAC supports this finding: “In 2009, nearly 1.1 million Medicare beneficiaries received hospice services from nearly 3,500 providers, and Medicare expenditures totaled \$12 billion.” MEDICARE PAYMENT ADVISORY COMM'N, *supra* note 52, at 259.

98. NAT'L HOSPICE & PALLIATIVE CARE ORG., *supra* note 52, at 10 (89% of hospice patient days are covered by Medicare).

99. Billings, *supra* note 35, at 76.

100. *Id.* at 77 (most patients use hospice at the very end of life, usually in just the last weeks).

101. MEDICARE PAYMENT ADVISORY COMM'N, *supra* note 52, at 269.

number of short stays has remained steady with a median of 17 days.¹⁰² Further, the lowest 25% has actually decreased from an average stay of 6 days to just 5 days.¹⁰³ The same pattern is seen at nonprofit and for-profit hospices.¹⁰⁴

The Medicare hospice benefit has likely led to an increase in the number of for-profit hospices. Entrepreneurs lobbied for the hospice benefit because they saw a business opportunity.¹⁰⁵ Hospices receive a per diem rate for services based on the location and level of care.¹⁰⁶ They receive this daily payment no matter how many services they provide.¹⁰⁷ Although an individual hospice is limited in the amount of Medicare payments it can receive each year,¹⁰⁸ this does not appear to have significantly retarded the for-profit hospice industry's growth.¹⁰⁹ In fact, the growth of the for-profit hospice industry has been enormous: between 1992 and 1999, for-profit hospice centers increased by 300%¹¹⁰ and an additional 142% between 2000 and 2009.¹¹¹

Such significant increases have led researchers to ask whether for-profit status affects quality of care.¹¹² Whereas nonprofit hospice has emerged from a care tradition with an emphasis on "psychosocial support, spiritual

102. *Id.*

103. *Id.* MedPAC attributes the short stays to factors other than the Medicare benefit including reluctance on the part of physicians and family member to admit a patient to hospice and patient unwillingness to forego curative treatment. *Id.* Ironically, these two issues could be seen as stemming from the Medicare benefit's exacting requirements that a physician certify a patient has less than six months to live and that a patient forego curative treatment for eligibility. *Id.*

104. Melissa D. A. Carlson et al., *Ownership Status and Patterns of Care in Hospice, Results from the National Home and Hospice Care Survey*, 42 MED. CARE 432, 437 (2004) (finding, in their study, no difference of the length of stay between for-profit and non-profit hospice).

105. Joshua E. Perry & Robert C. Stone, *In the Business of Dying: Questioning the Commercialization of Hospice*, 39 J.L. MED. & ETHICS 224, 227 (2011).

106. MEDICARE PAYMENT ADVISORY COMM'N, *supra* note 52, at 262. The four levels of care and payment are: Routine Home Care (\$147/day), Continuous Home Care (\$35.66/hour), Inpatient Respite Care (\$152/day), and General Inpatient Care (\$652/day). *Id.*

107. Perry & Stone, *supra* note 105, at 227.

108. The only significant financial constraint on hospice expenditure growth, the cap requires hospices to repay Medicare for any payments received above the total number of Medicare patients electing hospice in their program times a set cap amount. In 2008, the cap amount was \$22,386.15. MEDICARE PAYMENT ADVISORY COMM'N, *supra* note 52, at 264.

109. In 2008, 10% of hospices were exceeding the cap. *Id.* at 271. The number of hospices who exceed the cap tends to be low, however, MedPAC notes that as the length of stay for the very long group increases, more hospices are exceeding the cap. *Id.* at 264.

110. Carlson et al., *supra* note 104, at 432.

111. MEDICARE PAYMENT ADVISORY COMM'N, *supra* note 52, at 267.

112. Carlson et al., *supra* note 104, at 432.

care, the use of volunteers and family, and symptom management," for-profit care may not have the same foundation and therefore, may lack quality.¹¹³ However, studies have been rare and inconsistent.¹¹⁴ One 2004 study did conclude that patients in for-profit hospice were receiving fewer non-core services than patients in nonprofit hospice settings.¹¹⁵ Others have shown that in a for-profit facility, there is less skilled nursing care¹¹⁶ and fewer interdisciplinary staff.¹¹⁷

Next, evidence suggests that hospices may be "cherry-picking" residents.¹¹⁸ Cherry-picking refers to the practice of choosing only those most desirable patients.¹¹⁹ For instance, the Medicare benefit's per diem structure incentivizes recruiting patients likely to live longer while needing fewer services.¹²⁰ According to MedPAC, very long stays have grown from an average of 141 days to an average of 237 days.¹²¹ Although "counterintuitive," longer stays actually are more profitable because of the U-shaped curve of the cost of providing hospice care.¹²² Patients tend to be more expensive at the beginning of their stay as they are acclimated to the hospice program, and at the end of their stay as more care is needed for comfort in the dying process, leaving a middle area (at the bottom of the U) where patients cost less.¹²³ Therefore, the longer a patient stays in hospice care, the longer the period of profit at the bottom of the U-curve.¹²⁴

This is a particularly troublesome problem in the for-profit setting. Lengths of stay are about 45% longer in for-profit hospice than in nonprofit

113. *Id.* at 437.

114. Only two studies in the field had been performed as of 2004: One finding that for-profit centers provided more bereavement services, the other finding no significant difference between for-profit and nonprofit care in terms of treatment hours or number of patient services. *Id.* at 432.

115. *Id.* at 435. Core services must be provided by the hospice organization at all times. CTRS. FOR MEDICARE & MEDICAID SERVS., MEDICARE BENEFIT POLICY MANUAL 40.4 (2012). Core services are: physician services, nursing services, medical social services, and counseling, including bereavement. *Id.* Non-core services must be provided to meet the patients' and families' needs. *Id.* at 40.5. They are: physical, occupational, and speech therapies, hospice aide services, homemaker services, volunteers, medical supplies including drugs and durable medical equipment, and short-term inpatient care. *Id.*

116. Perry & Stone, *supra* note 105, at 230.

117. *Id.*

118. See *id.* at 228.

119. Stephanie Bouchard, *Concerns Raised About Increase in For-Profit Hospice Care*, HEALTHCARE FIN. NEWS (May 26, 2011), <http://www.healthcarefinancenews.com/news/concerns-raised-about-increase-profit-hospice-care>.

120. Perry & Stone, *supra* note 105, at 229.

121. MEDICARE PAYMENT ADVISORY COMM'N, *supra* note 52, at 269.

122. Perry & Stone, *supra* note 105, at 228.

123. *Id.*

124. *Id.* at 228-29.

hospice.¹²⁵ Furthermore, patients in for-profit hospices are more likely to stay longer than a year in hospice.¹²⁶ The fact that for-profit hospice tends to generate more revenue than nonprofit hospice can be attributed to cherry-picking longer-stay patients.¹²⁷

An extension of this analysis provides an explanation for for-profit hospices' exclusion of cancerous patients, perhaps this rationale's most detrimental effect.¹²⁸ Wachterman et al. suggest:

under [the Medicare hospice per diem payment system], profit can be maximized by caring for patients with certain diagnoses that require fewer skilled services, patients residing in nursing homes, or patients with longer hospice stays.¹²⁹

Their study found that not only were for-profit hospices selecting non-cancerous patients, but also were specifically selecting dementia patients.¹³⁰ Therefore, two-thirds of for-profit hospice patients were diagnosed with dementia and had non-cancerous conditions whereas only one-half of nonprofit hospice patients have similar diagnoses.¹³¹ Further, dementia patients have significantly longer stays than all other patient types.¹³²

125. *Id.* at 228. Additionally patients stayed on average four days longer in for-profit hospice. Melissa W. Wachterman et al., *Association of Hospice Agency Profit Status With Patient Diagnosis, Location of Care, and Length of Stay*, 305 JAMA 472, 475 (2011).

126. Wachterman et al., *supra* note 125, at 476.

127. Perry & Stone, *supra* note 105, at 225. In fact, Vitas, the largest for-profit hospice provider in the nation, sends recruiters to nursing homes to select and influence residents. *Id.* at 228.

128. *Id.* at 229 (suggesting that dominant for-profit systems would push more costly patients, cancerous patients, off on hospices "with a broader commitment to a community"). What makes this so detrimental is that hospice's origins stem from its work with cancer patients. For a quick and dirty history of hospice, see *History of Hospice Care*, NAT'L HOSPICE & PALLIATIVE CARE ORG. (May 17, 2012), <http://www.nhpc.org/i4a/pages/index.cfm?pageid=3285>.

129. Wachterman et al., *supra* note 125, at 477.

130. For-profit hospices had 34.1% cancer patients as compared with 48.4% for nonprofit hospices. *Id.* Further, for profit had 17.2% of patients with dementia as compared with 8.4% and more patients with other diagnoses (48.7% v. 43.2%). *Id.* at 475. The National Hospice Organization (NHO) has issued physician certification standards for dementia: "Hospice criteria for dementia include: (1) dementia of sufficient severity and (2) the first occurrence of medical complications." Brad Stuart, *The NHO Medical Guidelines for Non-Cancer Disease and Local Medical Review Policy: Hospice Access for Patients with Diseases Other Than Cancer*, 14 HOSPICE J., no. 3/4, 1999, at 139, 146. However, even when following these guidelines, physician certification of non-cancerous patients is unreliable. For example, in Alzheimer's patients, with an unpredictable disease trajectory, only 30% of those certified died within 6 months of certification. Kiran Joshi et al., *How Do We Decide When a Patient with Nonmalignant Disease is Eligible for Hospice Care?*, 55 CLINICAL INQUIRIES 525, 529 (2006).

131. Wachterman et al., *supra* note 125, at 477.

132. *Id.* at 476.

Therefore, despite the proven value of palliative care, especially at the end of life in the form of hospice, palliative care's promise has been broken. The negative incentives of the Medicare hospice payment structure have led to a rise in for-profit hospice, perhaps lower quality of care, and either very long stays or very short stays.

2. Physician-Patient Communication Breakdown

Physician-patient end-of-life communication is absolutely necessary.¹³³ It helps physicians and patients work together to establish effective treatment plans.¹³⁴ Those who speak with their physician about end-of-life care are more likely to choose less aggressive treatment, to die at home or in hospice, and to have their treatment preferences followed.¹³⁵ As previously stated, patients who chose less aggressive treatment are more likely to have a better quality of life and are more likely to live longer.¹³⁶ Failure to adequately communicate negatively affects the quality of palliative care¹³⁷ as well as patient and caregiver satisfaction.¹³⁸ Further, inappropriate communication can *traumatize* the patient or the caregiver¹³⁹ and affect the patient's ability to adjust psychologically.¹⁴⁰

The principles of effective end-of-life communication are well established and an open conversation should occur as early as possible. For example, the Institute of Medicine (IOM) has published guidelines for communicating a bad prognosis to a patient.¹⁴¹ Generally, the IOM advises providers "to ask, not assume: to ask patients what they want to know, to suggest questions that patients might have" with attention to cultural sensitivities.¹⁴² The IOM also recommends that the end-of-life conversation

133. Eburn Abarshi et al., *Discussing End-of-Life Issues in the Last Months of Life: A Nationwide Study Among General Practitioners*, 14 J. PALLIATIVE MED. 323, 323 (2011).

134. See *id.*

135. Jennifer W. Mack et al., *End-of-Life Care Discussions Among Patients With Advanced Cancer*, 156 ANNALS INTERNAL MED. 204, 204 (2012).

136. *Id.* at 204, 207.

137. Abarshi et al., *supra* note 133, at 323.

138. Michelle N. Grainger et al., *Discussing the Transition to Palliative Care: Evaluation of a Brief Communication Skills Training Program for Oncology Clinicians*, 8 PALLIATIVE & SUPPORTIVE CARE 441, 442 (2010).

139. COMM. ON CARE AT THE END OF LIFE, INST. OF MED., *APPROACHING DEATH: IMPROVING CARE AT THE END OF LIFE* 61 (Marilyn J. Field & Christine K. Cassel eds., 1997).

140. Grainger et al., *supra* note 138, at 442.

141. See COMM. ON CARE AT THE END OF LIFE, INST. OF MED., *supra* note 139, at 62-63.

142. *Id.* at 64. An end-of-life conversation can be especially challenging in different cultural contexts. See, e.g., Alina M. Perez & Kathy L. Cerminara, *La Caja de Pandora: Improving Access to Hospice Care Among Hispanic and African-American Patients*, 10 HOUS. J. HEALTH L. & POL'Y 255, 257 (2010).

should occur early in the disease trajectory.¹⁴³ Similarly, national standards for patients with incurable cancer recommend that these conversations occur when a patient's life expectancy falls to within one year.¹⁴⁴

Unfortunately, despite established guidelines, these discussions are not occurring and when they are, they take place in the hospital, very shortly before a patient's death, and are not always effective. Some studies report that fewer than 40% of patients with advanced cancer are having end-of-life discussions with their physicians.¹⁴⁵ When they do occur, they take place, on average, just a month prior to death in the hospital setting.¹⁴⁶ Even when a physician shares information with a patient, there is no guarantee the information has been understood.¹⁴⁷ For example, one study of communication in the intensive care unit (ICU) found that patients' families left almost half the time feeling as though there had been a conflict with the ICU staff.¹⁴⁸ One especially disturbing example of such poor communication included in the report was that of "physicians saying that another patient needed the dying patient's bed."¹⁴⁹

Physicians acknowledge that these discussions at the end of a patient's life cause uncertainty and apprehension.¹⁵⁰ Emotionally, the physician may feel helpless or like she is failing the patient.¹⁵¹ Their education may not adequately prepare them for this experience. Despite the increase in medical school coursework hours devoted to palliative care and communication, most hours are spent in so-called "patient-interviewing courses," considered to have the "least effect on [a] medical student's competency."¹⁵² Further, in the so-called "hidden curriculum," physicians may be taught to be dismissive or even avoidant of palliative care.¹⁵³

143. See e.g., Grainger et al., *supra* note 138, at 441.

144. Mack et al., *supra* note 135, at 204.

145. *Id.*

146. *Id.* at 207. Mack et al. found that end-of-life conversations occurred 87% of the time but only within a month of death. *Id.*

147. COMM. ON CARE AT THE END OF LIFE, INST. OF MED., *supra* note 139, at 63.

148. Tomer T. Levin et al., *End-of-Life Communication in the Intensive Care Unit*, 32 GEN. HOSP. PSYCHIATRY 433, 433 (2010).

149. *Id.* at 434.

150. COMM. ON CARE AT THE END OF LIFE, INST. OF MED., *supra* note 139, at 61.

151. Grainger et al., *supra* note 138, at 441.

152. Joy Goldsmith et al., *Palliative Care Communication Curriculum: What Can Students Learn from an Unfolding Case?*, 28 AM. J. HOSPICE & PALLIATIVE MED. 236, 236 (2011).

153. *Id.* "Although a student can be prepared for excellent communication, collaboration, empathy, and patient centered attitudes through years of formal training, just a few minutes in a work environment that does not model these behaviors will rapidly lead to their extinction in the student's behaviors." Brian David Hodges & Ayelet Kuper, *Theory and Practice in the Design and Conduct of Graduate Medical Education*, 87 ACAD. MED. 25, 30 (2012) (explaining a medical student's exposure to the "hidden curriculum").

Communication between a physician and his patient, or the patient's caregiver, is vital at the end of life. However, evidence shows that when these conversations occur, many times they happen too late for the patient to access the promise of palliative care.

3. Inadequate Pain Management

Pain is defined as "an unpleasant sensation occurring in varying degrees of severity as a consequence of injury, disease or emotional disorder."¹⁵⁴ Pain management is "a comprehensive approach to the needs of patients . . . who experience problems associated with acute or chronic pain."¹⁵⁵ Approximately 116 million people currently suffer from a chronic pain condition and pain costs our country at least \$560 billion a year in economic losses.¹⁵⁶ As one advocate puts it, pain is more than just the sensation:

It is so much more than just pain intensity. Over time, many [patients] find the effects of living with chronic pain impact their ability to work, engage in recreational and social activities, and for some, [perform] the most basic everyday activities that people just take for granted. Not surprisingly, pain begins to chip away at their mood, often leaving them angry, frustrated, anxious, and/or depressed. Our families suffer along with us, and many relationships are forever altered.¹⁵⁷

Although most pain can be treated, healthcare providers do not have a strong track record in this area.¹⁵⁸ For example, the SUPPORT study found that 50% of people experienced pain even after a week of hospitalization.¹⁵⁹ Another study showed results as high as 79% of their survey group experiencing pain after seven days of hospitalization.¹⁶⁰ One explanation for

154. STEDMAN'S MEDICAL DICTIONARY 1282 (26th ed. 1995).

155. Barry R. Furrow, *Pain Management and Provider Liability: No More Excuses*, 29 J.L. MED. & ETHICS 28, 29 (2001).

156. COMM. ON ADVANCING PAIN RESEARCH, CARE, & EDUC. INST. OF MED., *RELIEVING PAIN IN AMERICA: A BLUEPRINT FOR TRANSFORMING PREVENTION, CARE, EDUCATION, AND RESEARCH* 1 (2011).

157. *Id.* at 24.

158. Furrow, *supra* note 155, at 28. In fact, there is "strong consensus" that 90% of all pain can be treated. Ben A. Rich, *A Prescription for the Pain: The Emerging Standard of Care for Pain Management*, 26 WM. MITCHELL L. REV. 1, 8 (2000).

159. Norman A. Desbiens et al., *Pain and Satisfaction with Pain Control in Seriously Ill Hospitalized Adults: Findings from the SUPPORT Research Investigations*, 24 CRITICAL CARE MED. 1953, 1954, 1959 (1996); MORRISON, *supra* note 36, at 3. The SUPPORT study evaluated the decision-making process in nine high mortality diseases: acute respiratory failure; chronic obstructive pulmonary disease; congestive heart failure; chronic liver failure; nontraumatic coma; metastatic colon cancer; advanced non-small cell lung cancer; multiple organ system failure with malignancy; and sepsis. Desbiens et al., *supra*, at 1954.

160. Desbiens et al., *supra* note 159, at 1959.

these differing results is that pain intensity can vary among disease types.¹⁶¹ The SUPPORT study concluded that those with colon cancer reported more pain than patients with other disease types.¹⁶² Cancer patients, therefore, may have different pain medication needs than those with other illnesses.¹⁶³ The wide variance of pain experiences among patients and its clear undertreatment underscore the importance of asking patients about their pain.¹⁶⁴

Various (mis?)perceptions cause physicians to under-prescribe. Many are the result of a lack of both physician and patient education in this area.¹⁶⁵ Physician pain management training is woefully inadequate,¹⁶⁶ and perhaps this leads to patients receiving little or no information about medication.¹⁶⁷ Both physician and patient fears, often unfounded, lead to under-prescription. Physicians' fear of legal action and avoidance of regulatory scrutiny are most commonly attributed to inadequate pain management.¹⁶⁸ Physicians also worry about patient addiction.¹⁶⁹ Similarly, patients' own fears of addiction may contribute to this misperception.¹⁷⁰

In the case of palliative sedation, an important form of pain management at the end of life, additional ethical factors may contribute to underprescription. Palliative sedation is the last, and usually the only, option for individuals who have no alternatives to treat their pain.¹⁷¹ Under palliative sedation, a patient can be rendered completely unconscious.¹⁷² The scientific community continues to debate when sedation is appropriate.¹⁷³ Of specific concern is how close to death a patient needs to be in order to receive this treatment.¹⁷⁴ Some physicians argue that the line

161. See *id.*

162. *Id.*

163. *Id.*

164. *Id.* at 1960.

165. See Rima J. Oken, *Curing Healthcare Providers' Failure to Administer Opioids in the Treatment of Severe Pain*, 23 *CARDOZO L. REV.* 1917, 1933 (2002).

166. *Id.* Oken notes that many medical schools offer pain management as a portion of another course, likely taught by someone without experience in palliative care. *Id.* at 1933-34.

167. See Furrow, *supra* note 155, at 28.

168. *Id.*

169. Rich, *supra* note 158, at 8. Especially in rural America, these fears may not be unfounded. See David L. Robinson, *Bridging the Gaps: Improved Legislation to Prohibit the Abuse of Prescription Drugs in Virginia*, 9 *APPALACHIAN J.L.* 281, 281 (2010).

170. Furrow, *supra* note 155, at 28.

171. Jeffrey T. Berger, *Rethinking Guidelines for the Use of Palliative Sedation*, *HASTINGS CENTER REP.*, May-June 2010, at 32, 33.

172. *Id.* at 32-33.

173. *Id.* at 33.

174. *Id.*

should be drawn at mere hours from death, while others suggest that palliative sedation should be available to the patient at the point of terminal diagnosis.¹⁷⁵ A great deal of this concern stems from the fact that palliative sedation can hasten a person's death.¹⁷⁶ However, palliative sedation is recognized as a patient's right even if it does accelerate death¹⁷⁷ and most individuals under palliative sedation die from the underlying illness, not the medication.¹⁷⁸

In addition to palliative sedation, many times caregivers must also decide whether to provide nutrition, contributing to the fundamental ethical dilemma. Consider the case of Mr. Oltzik, 88 years old, diagnosed with dementia, congestive heart failure, and kidney problems.¹⁷⁹ His wife and son could no longer take care of him at home because of his erratic behavior.¹⁸⁰ Once in the hospice center, physicians, with the support of his family, decided to provide his pain medication intravenously.¹⁸¹ His erratic behavior stopped and Mr. Oltzik appeared at peace.¹⁸² In addition to the decision to sedate her husband, Mrs. Oltzik had to also decide whether to provide her husband, unable to swallow, nutrition and hydration through a tube.¹⁸³ Ultimately his wife decided against insertion of a tube.¹⁸⁴

Much of the conversation had proceeded not in black and white like a legal document, but in shades of gray. By the end, they all seemed to understand one another, though ultimately Mrs. Oltzik would express some sadness at being unable to interact with her husband.¹⁸⁵

These decisions do indeed occur in shades of gray and only a physician appropriately educated in end-of-life issues can aptly guide families through a situation such as that of Mr. Oltzik and his family.

Physician and patient misperceptions, often born through a lack of education, can negatively impact an already difficult, multilayered, ethical decision to provide palliative sedation at the end of life. Therefore, despite

175. *Id.*

176. Berger, *supra* 171, at 32. Palliative sedation is distinguished from active euthanasia, however, because the treating physician's goal is to treat pain, not to kill the patient, an ethical phenomenon known as "double effect." *Id.* at 33-34.

177. See, e.g., *Washington v. Glucksberg*, 521 U.S. 702, 737-38 (1997) (O'Connor, J., concurring) ("There is no dispute that dying patients in Washington and New York can obtain palliative care, even when doing so would hasten their deaths.").

178. Berger, *supra* note 171, at 33.

179. Hartocollis, *supra* note 73.

180. *Id.*

181. *Id.*

182. *Id.*

183. *Id.*

184. Hartocollis, *supra* note 73.

185. *Id.*

the proven value of palliative care, the promise has been broken. Evidence suggests a rise in for-profit hospice, questionable quality of care, and very long stays or very short stays. Further complicating the picture is the breakdown of patient-physician communication and inadequate pain management at the end of life.

III. STATE-LEVEL ATTEMPTS & FAILURES

Unfortunately, the United States' healthcare system faces many challenges at the end of life. The fault lies not only with Medicare's incentives for for-profit hospice centers to cherry-pick residents and provide questionable quality care, but also with physicians. At the root of good patient care at the end of life is the physician-patient relationship. However, when communication lines falter or fail, inadequate pain management and other important patient needs go unattended. First, Part A will address two attempts at solving this problem: California's Right to Know End-of-Life Options Act¹⁸⁶ and New York's new 2011 statute.¹⁸⁷ Then Part B will discuss why a state level solution is not viable.

A. *Two Attempts: California and New York Tackle Physician-Patient Communication at the End of Life*

California and New York have tackled failures in patient-physician communication at the end of life by enacting legislation requiring physicians to communicate with patients or family members about end-of-life treatment decisions.¹⁸⁸ Called "right-to-know" laws,¹⁸⁹ both statutes focus on informing a patient of all available treatments at the end of life. However, they differ in several respects, including the duty they require of the physician, their approach to penalties and fines, and their potential role in litigation.¹⁹⁰ This section will first address California's elder abuse framework and then New York's use of its established public health laws.

1. California's Approach

This humane and compassionate legislation will assure those suffering at the end of their lives are provided full and accurate information about their

186. CAL. HEALTH & SAFETY CODE § 442.5 (West 2010).

187. N.Y. PUB. HEALTH LAW § 2997-c (McKinney 2011).

188. Right to Know End of Life Options Act, CAL. HEALTH & SAFETY CODE § 442.5 (West 2010); N.Y. PUB. HEALTH LAW § Right to Know End of Life Options Act, CAL. HEALTH & SAFETY CODE § 442; N.Y. PUB. HEALTH LAW §2997-c.

189. Thaddeus Mason Pope, *Health Law and the Elderly: Managing Risk at the End of Life: An Introduction to the Symposium*, 17 WIDENER L. REV. i, viii (2011).

190. See *infra* Part III.B.

treatment and pain management options — Assemblymember Lloyd Levine (speaking about the California Right to Know End-of-Life Options Act)¹⁹¹

In 2008, California Governor Arnold Schwarzenegger signed into law the Right to Know End-of-Life Options Act (Right to Know Act).¹⁹² Advocates saw this as a victory for patients, while medical professionals scoffed at the legislature's interference into their realm.¹⁹³ A question remains as to how important this law has been and how legal professionals can use it to support their clients. First this section will review the Right to Know Act, paying specific attention to the battle to get it passed in its current form, the language with some of its noticeable flaws, and the continued debate over its intrusion into the physician-patient relationship. The next part will address the legal implications of the statute as exemplified by the current litigation — *Hargett v. Vitas*.¹⁹⁴

a. California's Right to Know Statute

The Right to Know Act grew from a legislative effort to recognize the importance of hospice and palliative care, that too few Californians were receiving hospice care, and the dangers surrounding the breakdown of communication between physician and patient. Its narrow approval perhaps reflects negative legislative and public opinion of previous end-of-life measures.¹⁹⁵ In prior years, more expansive legislation allowed Californians to request medication to “provide comfort with an assurance of peaceful dying if suffering becomes unbearable.”¹⁹⁶ Earlier versions of the Right to Know Act included more specific information about voluntarily stopping eating and drinking (VSED) as well as about palliative sedation.¹⁹⁷

191. Frank D. Russo, *California Assembly Approves Right to Know End-of-Life Options Act*, CAL. PROGRESS REPORT (May 30, 2008), <http://www.californiaprogressreport.com/site/california-assembly-approves-right-know-end-life-options-act>.

192. A.B. 2747, 2007-2008 Leg., (Cal. 2008), available at http://www.leginfo.ca.gov/pub/07-08/bill/asm/ab_2701-2750/ab_2747_bill_20080930_chaptered.pdf (Gov. Schwarzenegger signed the bill into law on Sept. 30, 2008).

193. Kevin B. O'Reilly, *California Law Mandates Discussing End-of-Life Options*, AM. MED. NEWS (Nov. 10, 2008), <http://www.ama-assn.org/amednews/2008/11/10/prsc1110.htm>.

194. Initial Complaint, *Hargett v. Vitas*, No. RG10547255 (Cal. Super. Nov. 18, 2010).

195. The vote was 42-34 with all the Republican House members, joined by two Democrats, voting against the measure. Russo, *supra* note 191.

196. The California Compassionate Choices Act (A.B. 651, 2005-06 Leg., Reg. Sess. (Cal. 2005)) was reintroduced in the next legislative term (A.B. 374, 2007-2008 Leg., (Cal. 2007)). Interestingly, a majority of Californians supported the bill. Russo, *supra* note 191.

197. Ben A. Rich, *Legislating Patient-Care Protocols*, UC DAVIS HEALTH SYSTEM (2012), http://www.ucdmc.ucdavis.edu/welcome/features/20090513_Medicine_Rich/index.html [hereinafter Rich, *Legislating Patient-Care Protocols*]. Voluntarily Stopping Eating and Drinking (VSED) is a method of hastening death when a patient chooses to not accept hydration or

Legislators on the floor had to distinguish the Right to Know Act from these previous attempts at passing end-of-life measures and versions of the bill in order to get it passed.¹⁹⁸ One commentator noted that this was in fact a “modest measure dealing only with a patient’s right to be informed.”¹⁹⁹

The first of its kind,²⁰⁰ the statute requires a healthcare provider, when she makes a terminal diagnosis, to, “upon a patient’s request, provide the patient with comprehensive information and counseling regarding legal end-of-life care options.”²⁰¹ This includes information about:

The patient’s right to comprehensive pain and symptom management at the end of life, including, but not limited to, adequate pain medication, treatment of nausea, palliative chemotherapy, relief of shortness of breath and fatigue, and other clinical treatments useful when a patient is actively dying.²⁰²

Physicians may still inform patients about VSED and palliative sedation but such language was not included in the final version of the bill.²⁰³

Similar to the Medicare hospice benefit, timing is at issue in the Right to Know Act. The Right to Know Act fails to explicitly define “terminal illness.”²⁰⁴ A different section of the welfare act defines “terminal disease” as “a medical condition resulting in a prognosis of life of one year or less, if the disease follows its natural course.”²⁰⁵ Assuming that this language is applicable, physicians are given more time than with the Medicare hospice benefit.²⁰⁶ However, similar to the Medicare benefit, such timelines create a lot of uncertainty on the part of the physician.²⁰⁷ Patient advocates are also concerned that the act does not offer sufficient leeway for individuals who have “‘seriously compromised and declining health,’ or those who are chronically ill, frail and ‘at high risk of dying at a time uncertain.’”²⁰⁸

nutrition. Thaddeus Mason Pope & Lindsey E. Anderson, *Voluntarily Stopping Eating and Drinking: A Legal Treatment Option at the End of Life*, 17 WIDENER L. REV. 363, 383 (2011).

198. Russo, *supra* note 191.

199. *Id.*

200. O’Reilly, *supra* note 193.

201. CAL. HEALTH & SAFETY CODE § 442.5 (West 2010).

202. *Id.* § 442.5(a)(5).

203. O’Reilly, *supra* note 193. The law requires that healthcare providers “provide the patient with comprehensive information” which may include VSED and palliative sedation. *Id.*; CAL. HEALTH & SAFETY CODE § 442.5.

204. CAL. HEALTH & SAFETY CODE § 442.

205. *Id.* § 1746(i).

206. 42 C.F.R. § 418.20 (2011); Billings, *supra* note 35, at 76.

207. Billings, *supra* note 35, at 76.

208. Ruth C. Stern & J. Herbie DiFonzo, *Stopping for Death: Re-Framing our Perspective on the End-of-Life*, 20 U. FLA. J.L. & PUB. POL’Y 387, 434 (2009).

Despite the California Medical Association's (CMA) support for the measure,²⁰⁹ physicians still express concern that the law "unduly interferes with the physician-patient relationship."²¹⁰ Specifically, they argue that such legislation may result in "information dumping."²¹¹ Such information overload, physicians fear, would preclude them from having detailed conversations with patients at the appropriate times.²¹² Supporters argue that they "'don't think physicians need to be afraid of overwhelming patients with too much information when they are following the patients' lead.'"²¹³

Although contentious and flawed, the Right to Know Act is California's attempt at a solution to the physician-patient communication conundrum. The next section will address how it might be used in litigation to affect change.

b. Right to Know Act Meets Elder Abuse Litigation, a Legal Solution?

Carol Hargett realized that her daughter, Michelle Hargett-Beebee, had died when she heard her moans stop.²¹⁴ Michelle, a young mother, had died agonizingly in the care of a large for-profit hospice, Vitas.²¹⁵ The hospice staff was aware from early on that Ms. Hargett-Beebee was suffering and failed to adequately address her pain.²¹⁶ In 2010, Compassion & Choices filed suit against Vitas under an elder abuse theory.²¹⁷ In this case, however, the plaintiffs had a new weapon to add to their elder abuse allegations: California's Right to Know End-of-Life Options Act (Right to Know Act).²¹⁸

Although bringing an elder abuse claim given Michelle's age of 43 may seem unusual,²¹⁹ California's response to inadequate pain management

209. Rich, *Legislating Patient-Care Protocols*, *supra* note 197.

210. O'Reilly, *supra* note 193.

211. Rich, *Legislating Patient-Care Protocols*, *supra* note 197.

212. *Id.*

213. O'Reilly, *supra* note 193 (quoting Barbara Combs Lee, president of Compassion & Choices).

214. *A Death, a Tragedy, a Ground-Breaking Lawsuit*, COMPASSION & CHOICES, <http://community.compassionandchoices.org/page.aspx?pid=482> (last visited Nov. 28, 2012) [hereinafter *A Death, a Tragedy, a Ground-Breaking Lawsuit*].

215. *Id.*

216. *Id.*

217. Amended Complaint, *supra* note 11, at 16.

218. CAL. HEALTH & SAFETY CODE § 442.5 (West 2010); Amended Complaint, *supra* note 11, at 20.

219. Amended Complaint, *supra* note 11, at 3. See ELDER ABUSE FORENSIC CTR., APS STATISTICS AND 2005 CLIENT PROFILES (2005), available at http://www.elderabuseforensiccenter.com/pdf/eafc_elderabusereports.pdf (30% of reported adult abuse cases in 2005 were for non-elders aged 18-64); see CAL. DEP'T OF SOC. SERVS., ADMIN. DIV., ADULT PROTECTIVE

has been to bring causes of action under the state's elder abuse statute.²²⁰ Attorneys pursue this route for several reasons. First, despite a push to hold physicians accountable under medical malpractice, such attempts have been largely unsuccessful given the disparate standards for pain management.²²¹ Further, in California's case, there is a cap on medical malpractice damages, making this route unattractive.²²² On the other hand, in an action for elder abuse, if the physician acted with recklessness, oppression, fraud, or malice, the plaintiff can recover compensatory damages, attorney fees and costs, and damages for the decedent's pain and suffering.²²³

To be found liable under an elder abuse claim, the plaintiff must prove neglect or physical abuse of an elder or vulnerable dependent.²²⁴ Relevant in this discussion, neglect is defined as:

The negligent failure of any person having the care or custody of an elder or a dependent adult to exercise that degree of care that a reasonable person in a like position would exercise.²²⁵

In order to qualify for heightened remedies, one must also be found guilty of "recklessness, oppression, fraud, or malice."²²⁶ Recklessness is defined as a "subjective state of culpability greater than simple negligence, which has been described as a 'deliberate disregard' of the 'high degree of probability' that an injury will occur."²²⁷ Healthcare professionals may be found liable under two causes of action, medical malpractice and elder abuse, because, in the eyes of the California Supreme Court, these can be two separate claims.²²⁸

SERVICES (APS) ACTIVE CASES JULY 2006 - JUNE 2012 (2012), available at <http://www.cdss.ca.gov/research/res/pdf/daptrends/SOC242M1Active.pdf>.

220. Elder Abuse and Dependent Adult Civil Protection Act, CAL. WELF. & INST. § 15600-15675 (West 2011); see, e.g., *Bergman v. Chin*, No. CH205732 (Cal. Super Feb. 16, 1999).

221. Gilah R. Mayer, *Bergman v. Chin: Why an Elder Abuse Case is a Stride in the Direction of Civil Culpability for Physicians who Undertreat Patients Suffering from Terminal Pain*, 37 NEW ENG. L. REV. 313, 316 (2003).

222. CAL. WELF. & INST. § 3333.2 (limiting non-economic losses to no more than \$250,000).

223. *Id.* § 15657; Robert A. Mead, *Unpublished Opinions and Citation Prohibitions: Judicial Muddling of California's Developing Law of Elder and Dependent Adult Abuse Committed by Health Care Providers*, 37 WM. MITCHELL L. REV. 206, 207-08 (2010).

224. CAL. WELF. & INST. § 15657.

225. *Id.* § 15610.57.

226. *Id.* § 15657.

227. *Delaney v. Baker*, 971 P.2d. 986, 991 (Cal. 1999).

228. *Id.* at 997. Despite the availability of the heightened remedy under the Elder Abuse Statute, the court found the case to be "in fact" based on professional negligence. Mayer, *supra* note 221, at 343.

A 2001 case, *Bergman v. Chin*, paved the path for this new legal theory.²²⁹ In 1998, William Bergman, 85 years old, against his wish to die in peace, died in agony.²³⁰ After going to the emergency room at Eden Medical Center, he was prescribed a very low dose of pain medication as well as medication PRN.²³¹ Mr. Bergman's lung cancer had spread, causing his bones to fracture.²³² Over the next six days, he rated his pain from 7 up to 10 on a 10-point scale, indicating moderate to severe pain.²³³ His family notified physicians but little to no action was taken.²³⁴ He died three days later at home.²³⁵ His daughter subsequently reached out to a California nonprofit advocacy group, Compassion & Choices,²³⁶ for help filing suit.²³⁷ They filed an elder abuse case against Dr. Chin, the treating physician.²³⁸ Specifically, the plaintiff argued that Dr. Chin had been reckless when he neglected to establish a regimented pain management program for Mr. Bergman.²³⁹

The *Bergman* jury found Dr. Chin had committed reckless neglect when he failed to adequately treat Mr. Bergman's pain.²⁴⁰ Although they awarded the plaintiffs \$1.5 million in damages, the Court reduced the jury award to \$250,000 under the Medical Injury Compensation Reform Act (MICRA).²⁴¹ Therefore, although heightened remedies may be available in an elder abuse claim against a medical professional, they were not applied here.²⁴² The lasting importance of the *Bergman* case is not the amount of damages awarded but instead that inadequate treatment of pain can be found as reckless neglect under an elder abuse theory.²⁴³

229. *Bergman v. Chin*, No. CH205732 (Cal. Super Feb. 16, 1999); Tyche Hendricks, *Patient Never Complained, Says Doctor at Pain Trial*, S.F. CHRON., June 6, 2001, at A17 (noting that the *Bergman* case is the first of its kind).

230. Mayer, *supra* note 221, at 327, 329; Hendricks, *supra* note 229, at A17.

231. Mayer, *supra* note 221, at 327-28. PRN stands for "pro re nata," meaning as the situation demands. STEDMAN'S MEDICAL DICTIONARY, *supra* note 154, at 1427.

232. Mayer, *supra* note 221, at 328.

233. *Id.*

234. *See id.*

235. *Id.* at 329.

236. At the time Compassion & Choices was called the Compassion in Dying Federation. Compassion & Choices, *Timeline*, COMPASSION & CHOICES (2012), <http://www.compassionandchoices.org/who-we-are/timeline/>.

237. Mayer, *supra* note 221, at 329.

238. *Id.* at 330.

239. *Id.* at 333.

240. *Id.* at 340.

241. *Id.* at 341-42.

242. *See* Mayer, *supra* note 221, at 341-44 for a complete discussion of the MICRA and its applicability to pain cases under California's Elder Abuse framework.

243. *Id.* at 341.

Plaintiffs in the *Hargett* case argue that the Right to Know Act reinforces a physician's duty to ensure that Ms. Hargett-Beebee was fully informed of all available treatments for pain,²⁴⁴ a duty that has already been established under informed consent.²⁴⁵ By strengthening the physician's duty, plaintiffs hope to make a case for recklessness.²⁴⁶ If successful, this landmark case will establish that failure to communicate with a patient about pain management options, including palliative sedation, falls outside of the standard of care.²⁴⁷

In California, the Right to Know Act establishes a conditional duty on the part of the physician to discuss end-of-life options with her terminally ill patients. The act may bolster a claim of recklessness, as seen in *Hargett*, by strengthening the argument that a physician's duty to speak to a patient about pain medication at the end of life is well-established.

2. New York Follows with the Palliative Care Information Act

In 2010, New York followed in California's footsteps, enacting the Palliative Care Information Act (PCIA).²⁴⁸ Heralded as an "important step" to encourage trust and communication between patients and physicians,²⁴⁹ PCIA also requires physicians to discuss end-of-life options with terminally ill patients.²⁵⁰ PCIA states that physicians "shall" speak to patients upon their terminal diagnosis about at least but not limited to "the range of options appropriate to the patient; the prognosis, risks and benefits of the various

244. Amended Complaint, *supra* note 11, at 20-21.

245. *Id.* at 20.

246. *Id.* at 21.

247. *A Death, a Tragedy, a Ground-Breaking Lawsuit*, *supra* note 214. The case marches on as a battle of the briefs, even taking a trip to the state appellate court. Writ of Mandate, *Hargett v. Vitas*, No. A135036 (Cal. Ct. App. May 22, 2012). As of publication, the Plaintiffs have filed their third amended complaint, (Third Amended Complaint for Damages, *Hargett v. Vitas*, RG10547255 (Cal. Super. Feb. 8, 2013)), in response to Judge Dennis Hayashi's decision sustaining with leave to amend Defendants' demurrer regarding the claim for negligent infliction of emotional distress, (Order Sustaining in Part Defendants' Demurrer to Plaintiffs' Second Amended Complaint With Leave to Amend, *Hargett v. Vitas*, RG10547255 (Cal. Super. Jan. 30, 2013)), and the Defendants have filed a third demurrer, (Demurrer to Plaintiffs' Third Amended Complaint, *Hargett v. Vitas*, RG10547255 (Cal. Super. Feb. 26, 2013)) with a hearing on the demurrer scheduled for May 22, 2013. Importantly, the California Appellate Decision allowing Plaintiffs to amend their original complaint as to their negligent infliction of emotional distress claims is the first to recognize that a hospice may owe a duty directly to a patient's family. Writ of Mandate, *supra* 247.

248. N.Y. PUB. HEALTH LAW § 2997-c (McKinney 2011).

249. American Public Health Association, *New York Palliative Care Information Act Model for the Nation*, AGING & PUB. HEALTH SEC. NEWSL., Fall 2010, <http://www.apha.org/member-groups/newsletters/sectionnewsletters/aph/fall10/>.

250. N.Y. PUB. HEALTH LAW § 2997-c.

options; and the patient's legal rights to comprehensive pain and symptom management at the end of life."²⁵¹ Unlike the California statute, PCIA does not specifically list areas to be discussed.²⁵² It does, however, define terminal illness as "an illness or condition which can reasonably be expected to cause death within six months, whether or not treatment is provided."²⁵³ Similar to the California statute, physicians still consider this terminal illness language to be too forceful given the uncertainty in accurate prognostication of death.²⁵⁴

PCIA varies from California's Right to Know Act in two important ways. First, it affirmatively requires, without a patient's request, a physician to provide this information.²⁵⁵ This wording establishes an "affirmative duty" on the part of the physician. An affirmative duty is defined as "a duty to take a positive step to do something."²⁵⁶ In contrast, the California act specifically requires "upon request" that physicians fully inform terminal patients about their options.²⁵⁷ This is a "conditional duty," a "duty that is conditioned on the occurrence of an event other than the lapse of time."²⁵⁸ In California, legislators faced fierce opposition from the California Medical Association (CMA) and only gained support for the legislation when they revised the trigger for physicians from an affirmative to a conditional one.²⁵⁹ In order for a duty to arise for the physician, the patient must first specifically ask for the information.²⁶⁰ No such condition is required by the New York statute.²⁶¹

Second, a violation of the PCIA can come with fines of up to \$10,000 and incarceration for willful violations of up to a year.²⁶² Some controversy surrounds the impression that the statute itself contains the monetary and jail time penalties.²⁶³ However, this belief is blatantly incorrect. Under the New York Public Health Law, any violations of its laws are subject to a fine or jail time.²⁶⁴ This differs from the California system in which individual sections

251. *Id.*

252. *Id.*; CAL. HEALTH & SAFETY CODE § 442.5 (West 2010).

253. N.Y. PUB. HEALTH LAW § 2997-c(d).

254. Alan B. Astrow & Beth Popp, *The Palliative Care Information Act in Real Life*, 364 NEW ENG. J. MED. 1885, 1886 (2011).

255. N.Y. PUB. HEALTH LAW § 2997-c.

256. BLACK'S LAW DICTIONARY 580 (9th ed. 2009).

257. CAL. HEALTH & SAFETY CODE § 442.5 (West 2010).

258. BLACK'S LAW DICTIONARY, *supra* note 256, at 580.

259. Rich, *Legislating Patient Care Protocols*, *supra* note 197.

260. CAL. HEALTH & SAFETY CODE § 442.5.

261. N.Y. PUB. HEALTH LAW § 2997-c (McKinney 2011).

262. *Id.* § 12 (violations); *Id.* § 12-b. The \$10,000 penalty will be reduced to no more than \$2,000 per violation as of April 1, 2014. *Id.* § 12.

263. Astrow & Popp, *supra* note 254, at 1885 (implying that the fine and jail term are specific to PCIA).

264. N.Y. PUB. HEALTH LAW § 12 (violations); *Id.* § 12-b.

have penalties instead of an overarching penalty for the entire Health and Safety Code.²⁶⁵ The Right to Know Act's codification does not include a penalty for violations.²⁶⁶

New York's approach to improving physician-patient communication is, in some ways, more stringent than that of California. Neither approach has been fully tested and controversy remains over their role in the physician-patient relationship.

B. *The Failures: Why a State-Level Solution is Inadequate*

A state law solution is not viable for two reasons: 1) the California and New York statutes have enforcement flaws and 2) both sweeping and uniform state-level changes seem unlikely. In New York, a physician may be fined up to \$10,000 per violation and may face incarceration of up to a year for any "willful" violation of the New York Public Health Law.²⁶⁷ Like the California elder abuse law, more than mere negligence is required.²⁶⁸ "Willful" is defined as a deliberate and voluntary action.²⁶⁹ Physicians have been convicted of willfully neglecting their patients under the public health laws of New York.²⁷⁰ However, a review of the cases brought under the statute shows that they fall into three distinct categories: obvious medical malpractice cases, illegal drug distribution, or fee-splitting arrangements.²⁷¹ The low number of cases could indicate that physicians are not being held accountable under this statute, or that, if they are, the penalties are not significant enough to fight in court. Adding in the political backlash of the PCIA,²⁷² it seems highly unlikely that physicians will be significantly motivated by a PCIA violation.

Additionally, other avenues of enforcement in New York do not seem possible. Whereas California has some of the most protective elder abuse

265. See, e.g., CAL. HEALTH & SAFETY CODE § 122356 (West 2010) (providing the penalties to a pet store owner in violation of their statutorily defined duties).

266. *Id.* § 442.5.

267. N.Y. PUB. HEALTH LAW §§ 12, 12-b.

268. *People v. Coe*, 501 N.Y.S.2d 997, 1000 (N.Y. Sup. Ct. 1986).

269. *Id.*

270. See, e.g., *People v. Einaugler*, 618 N.Y.S.2d 414 (N.Y. App. Div. 1994) (upholding a New York Supreme Court decision that a physician had violated 12-b of the Public Health Law when he failed to rush a patient to the hospital after giving her numerous feedings through peritoneal dialysis catheter which he mistook as her feeding tube); *People v. Angelakos*, 512 N.E.2d 305 (N.Y. App. Div. 1987) (upholding a physician's conviction under the Public Health Law for an illegal fee splitting arrangement with her landlord).

271. Using Westlaw, I reviewed cases referencing N.Y. PUB. HEALTH LAW § 12-b and the term "physician." This search method produced only 23 results, none from the last three years (2012-2009). Of these cases only seven were relevant; one was a medical malpractice case, four were related to illegal drugs, and two were illegal fee-splitting arrangements.

272. See, e.g., *Astrow & Popp*, *supra* note 254, at 1885.

laws in the country,²⁷³ New York does not have a similar civil statute.²⁷⁴ Therefore, in New York, an elder abuse claim for monetary damages would not be possible. New York attorneys could approach cases like *Hargett* through medical malpractice; New York does not have a cap on damages.²⁷⁵ Perhaps PCIA could be used to further strengthen the argument that the duty is well-known and therefore disregarding the duty would be reckless, similar to the plaintiff's argument in *Hargett*. However, as previously noted,²⁷⁶ evidence suggests that pain management medical malpractice cases can be hard to prove given differing pain management standards.²⁷⁷

California's Right to Know Act will also face enforcement challenges. Although California has a stronger elder abuse framework than New York,²⁷⁸ this enforcement strategy has several flaws. First, heightened remedies are only afforded to those cases in which "recklessness" can be proved.²⁷⁹ Recklessness is defined in *Delany* as a "subjective state of culpability greater than simple negligence, which has been described as a 'deliberate disregard' of the 'high degree of probability' that an injury will occur."²⁸⁰ Although *Bergman* established that this "recklessness" standard could apply to inadequate pain management,²⁸¹ neither *Delany* nor *Bergman* establishes where the line between professional negligence and reckless neglect can be drawn.²⁸²

Also, if an action can be brought under an elder abuse theory, as it has been in *Bergman*,²⁸³ *Hargett* and other similar cases remain undecided as to

273. Amanda Bassen, *Patient Neglect in Nursing Homes and Long-Term Care Facilities in New York State: The Need for New York to Implement Programs and Procedures to Combat Elder Neglect*, 8 CARDOZO PUB. L. POL'Y & ETHICS J. 179, 198-99 (2009).

274. Both New York and California provide criminal penalties for elder abuse. CAL. PENAL CODE § 368 (West 2010); N.Y. PENAL LAW §§ 260.31-260.34 (McKinney 2011). In New York, elder abuse is treated as an enhanced sentencing requirement with an underlying charge of assault or battery. *Id.*

275. Joel Stashenko, *Cap to Limit Non-Economic Awards Fails in Negotiations*, N.Y. L.J., March, 29, 2011 at 1, 1.

276. See *supra* Part III.A.1 (explaining the application of the California Right to Know Statute in the context of an elder abuse claim).

277. Mayer, *supra* note 221, at 316.

278. Bassen, *supra* note 273, at 198-99.

279. CAL. WELF. & INST. CODE § 15657.

280. *Delaney v. Baker*, 971 P.2d. 986, 991 (Cal. 1999).

281. See *supra* Part III.A.1 (explaining the application of the California Right to Know Statute in the context of an elder abuse claim).

282. Mead, *supra* note 223, at 217.

283. *Bergman v. Chin*, No. CH205732 (Cal. Super Feb. 16, 1999).

who may be covered by the elder abuse statute.²⁸⁴ Ms. Hargett-Beebee was not an elder adult.²⁸⁵ Instead, the plaintiffs are arguing she was a “dependent adult” because of her physical illness at the end of life.²⁸⁶ However, Ms. Hargett-Beebee may not fall under the elder abuse statute’s definition.²⁸⁷ Relying on the statute’s legislative intent,²⁸⁸ the defendants in the *Hargett* case argue that her inclusion may implicate the inclusion of every individual at the end of life.²⁸⁹ However, perhaps the statute should protect every individual at the end of life because almost every individual reaches old age and is afforded the protections of the law. Regardless, there is some doubt as to whether the courts will extend this protection.²⁹⁰ Further, if the *Hargett* theory does prevail, damages could be limited as they were in the *Bergman* case.²⁹¹

Currently, California and New York are the only states that have explicit right to know laws.²⁹² Several states have introduced some form of a right to know bill with varied success.²⁹³ However, a state-by-state solution would take time. One possibility could be the promulgation and passage of a Uniform Law Commission (ULC) uniform or model act that states could then

284. See Defendants’ Demurrer, *Hargett v. Vitas*, No. RG10547255 (Cal. Super. July 21, 2011) (arguing that the Plaintiffs’ had failed to state a claim for relief under an elder abuse theory).

285. Amended Complaint, *supra* note 11, at 6. Ms. Hargett-Beebee was 43 at the time of her death. *Hargett v. Vitas*, COMPASSION & CHOICES (2012), <http://www.compassionandchoices.org/what-we-do/in-the-courts/hargett-v-vitas/>. “Elder” means any person residing in this state, 65 years of age or older. CAL. WELF. & INST. CODE § 15610.27 (West 2010).

286. Amended Complaint, *supra* note 11, at 6. CAL. WELF. & INST. CODE § 15610.23 (“(a) ‘Dependent adult’ means any person between the ages of 18 and 64 years who resides in this state and who has physical or mental limitations that restrict his or her ability to carry out normal activities or to protect his or her rights, including, but not limited to, persons who have physical or developmental disabilities, or whose physical or mental abilities have diminished because of age. (b) ‘Dependent adult’ includes any person between the ages of 18 and 64 years who is admitted as an inpatient to a 24-hour health facility.”).

287. CAL. WELF. & INST. CODE § 15610.23.

288. Defendants’ Demurrer, *supra* note 284, at 5.

289. *Id.*

290. Defendants have attempted to make this argument, though a court has yet to decide on it. *Id.*

291. Mayer, *supra* note 221, at 342.

292. CAL. HEALTH & SAFETY CODE § 442.5 (West 2010); N.Y. PUB. HEALTH LAW § 2997-c (McKinney 2011).

293. See, e.g., S.B. 1311, 49th Leg., 1st Reg. Sess. (Ariz. 2009) (modeled off the California statute; failed); see, e.g., H.B. 30, 2009 Leg., Reg. Sess. (Md. 2009) (as introduced in the first reading similar to the New York statute; failed); see, e.g., H. 435, 2009-2010 Leg. Sess., (Vt. 2009) (framed as a bill of rights; passed!).

adopt.²⁹⁴ A proposal has been introduced to the Uniform Law Commission's Committee on Scope and Program²⁹⁵ recommending that a uniform state statute requiring conversations at the end of life be promulgated.²⁹⁶ The uniform law theory has not picked up steam, as the most recent petition was denied.²⁹⁷ Even if it were to gain momentum, a question remains as to what the uniform statute would look like. Although the New York right to know law, PCIA, provides criminal penalties,²⁹⁸ the California statute does not.²⁹⁹ Another important question is whether the physician's duty would be affirmative, like in PCIA, or conditional, like in the California Right to Know Act.³⁰⁰

A state level solution may not be effective at this point. Both California and New York's right to know statutes face enforcement challenges and a uniform model act not only does not seem likely, but also raises issues as to how such an act would be modeled.

IV. A FEDERAL SOLUTION?

A federal standard would not only eliminate the issue of uniformity among the states, but could also be a signal to physicians of the importance of this end-of-life conversation. However, recent events have shown that a legislative remedy would likely not be feasible.³⁰¹ Fears of "death panels" and "pull the plug on Grandma" effectively quashed earlier versions of the Affordable Care Act.³⁰² Although Section 1233 of H.R. 3200, an "advance planning consultation" provided for just that, a conversation,³⁰³ fears of

294. The Uniform Law Commission (ULC) studies current relevant state law issues, writes model acts, and then advocates for their implementation at the state level. *About the ULC*, UNIF. LAW COMM'N (2012), [http://uniformlaws.org/Narrative.aspx?title=About the ULC](http://uniformlaws.org/Narrative.aspx?title=About%20the%20ULC).

295. The Committee on Scope and Program is responsible for setting the commission's agenda. *Types of Committees*, UNIF. LAW COMM'N (2012), [http://uniformlaws.org/Narrative.aspx?title=Types of Committees](http://uniformlaws.org/Narrative.aspx?title=Types%20of%20Committees).

296. UNIF. LAW COMM'N, MIDYEAR MEETING OF THE COMMITTEE ON SCOPE AND PROGRAM 9-10 (2011), available at <http://uniformlaws.org/Shared/Docs/Scope%20Minutes%201-7-2011%20Final.pdf>.

297. *Id.*

298. N.Y. PUB. HEALTH LAW § 2997-c (McKinney 2011); Astrow & Popp, *supra* note 254, at 1885.

299. CAL. HEALTH & SAFETY CODE § 442.5 (West 2010).

300. *Id.*; N.Y. PUB. HEALTH LAW § 2997-c.

301. Michelle Andrews, *Rather than Creating "Death Panels," New Law Adds to End-Of-Life Options*, WASH. POST (Sept. 7, 2010), <http://www.washingtonpost.com/wp-dyn/content/article/2010/09/03/AR2010090305173.html>.

302. *Id.*

303. America's Affordable Health Choices Act of 2009, H.R. 3200, 111th Cong. § 1233 (2009).

rationing healthcare at the end of life led to its removal from the bill.³⁰⁴ As the recent legislative debacles illustrate, partisanship and intense in-fighting has not subsided, further limiting the possibility of a federal legislative solution.³⁰⁵

Instead of opting for a legislative solution, a provision should be added to the Medicare Conditions of Participation (COPs) for hospitals. COPs are one of the two sets of requirements that healthcare entities must meet to qualify for Medicare reimbursement.³⁰⁶ The statutory authority for “conditions of participation” is generally found in the Medicare statute’s³⁰⁷ definition of the institution.³⁰⁸ For hospitals, this statutory authority is found under Section 1395x(e)(9).³⁰⁹ A hospital is an institution which “meets such other requirements as the Secretary finds necessary in the interest of the health and safety of individuals who are furnished services in the institution.”³¹⁰ These “other requirements,” or COPs, are codified at 42 C.F.R. § 482.³¹¹ The Centers for Medicare and Medicaid Services develop

304. Christi Parsons & Andrew Zajac, *Senate Committee Scraps Healthcare Provision That Gave Rise to ‘Death Panel’ Claims*, L.A. TIMES (Aug. 14, 2009), <http://articles.latimes.com/2009/aug/14/nation/na-health-end-of-life14>.

305. See, e.g., Carl Hulse, *Tensions Escalate as Stakes Grow in Fiscal Clash*, N.Y. TIMES, (July 13, 2011), <http://www.nytimes.com/2011/07/14/us/politics/14fiscal.html?pagewanted=all>.

306. Healthcare entities must meet certain requirements to qualify for Medicare reimbursement including conditions of participation (Part A) and conditions of coverage (Part B). FURROW ET AL., *supra* note 20, at 547-48. Medicare Part A coverage includes hospital care whereas Part B provides for outpatient services. *Id.* at 541 (Medicare Part A “covers hospital care for up to ninety days for any ‘spell of illness,’ plus up to sixty ‘life time reserve days’ available on a one time basis. . . . For hospital patients, Medicare part A covers semiprivate accommodations; ordinary nursing services; use of hospital facilities and social services; drugs, biologicals, supplies, appliances and equipment ordinarily furnished in the hospital for hospital care; and other diagnostic or therapeutic items or services ordinarily furnished by the hospital to inpatients.”); *id.* at 542-43 (Medicare Part B covers: physician services, physician office services and supplies, outpatient and partial hospital services, outpatient diagnostic services, outpatient physical, occupational and speech therapy and more). For a complete list see *id.* at 543-44.

307. Social Security Amendments of 1965, Pub. L. No. 89-97, § 102, 79 Stat. 286, 291 (1965) (codified at 42 U.S.C. § 1305 (2012)); FURROW ET AL., *supra* note 20, at 550.

308. FURROW ET AL., *supra* note 20, at 550.

309. In 1965, section 102 of the Social Security Amendments of 1965 created “Health Insurance for the Aged.” Social Security Amendments, § 102. Section 1861 was added defining a “hospital.” *Id.* This provision has been codified as amended at 42 U.S.C. § 1395x(e)(9) (2012); FURROW ET AL., *supra* note 20, at 547-48.

310. 42 U.S.C. § 1395x(e)(9).

311. 42 C.F.R. § 482 (2011) (Conditions of Participation for Hospitals); *id.* § 488.1 (defining “conditions of participation” as “the requirements providers other than skilled nursing facilities must meet to participate in the Medicare program and includes conditions of certification for rural health clinics”).

the COPs³¹² while state survey agencies review hospital compliance.³¹³ A hospital may be removed from a state survey agency's list if the Joint Commission or the American Osteopathic Association accredits it.³¹⁴ No matter the path, a hospital must meet or exceed the COPs in order to receive Medicare reimbursement.³¹⁵

Although conditions of participation are required for all healthcare facilities, excluding nursing homes,³¹⁶ this paper focuses on those of hospitals because most individuals find themselves at the end of life in a hospital setting and are more likely to be diagnosed with a terminal illness in this same setting.³¹⁷ Additionally, hospital conditions of participation include hospital outpatient services.³¹⁸ The reach of hospital COPs may increase with the advent of the Accountable Care Organization.³¹⁹ COPs for these increasingly integrated organizations, which may include linked physician groups and hospitals, will likely be similar to those for hospitals.³²⁰

Conditions of participation, like most agency regulations,³²¹ must go through an informal rule-making process.³²² First, CMS releases a notice of proposed rulemaking in the federal register.³²³ After publication, a period

312. *Conditions for Coverage (CFCs) and Conditions of Participations (COPs)*, CTRS. FOR MEDICARE & MEDICAID SERVS. (May 11, 2012), https://www.cms.gov/CFCsAndCoPs/01_Overview.asp#TopOfPage [hereinafter CTRS. FOR MEDICARE & MEDICAID SERVS., *Conditions for Coverage*].

313. *Survey & Certification - Certification & Compliance*, CTRS. FOR MEDICARE & MEDICAID SERVS. (July 23, 2012), https://www.cms.gov/CertificationandCompliance/08_Hospitals.asp.

314. 42 C.F.R. § 488.3(b).

315. CTRS. FOR MEDICARE & MEDICAID SERVS., *Conditions for Coverage*, *supra* note 312.

316. 42 C.F.R. § 488.1.

317. See e.g., Levin et al., *supra* note 148, at 433 (22% of all deaths in the U.S. occur in the intensive care unit).

318. 42 C.F.R. § 482.54.

319. Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 3022, 124 Stat. 119, 395 (2010) (to be codified at 42 U.S.C. 1395). Very generally, an ACO is a group of providers working together to manage and coordinate care for Medicare fee-for-service beneficiaries. *Accountable Care Organizations (ACO)*, CTRS. FOR MEDICARE & MEDICAID SERVS. (Apr. 5, 2012), <https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/ACO/index.html?redirect=/ACO/>.

320. See Steven M. Lieberman & John M. Bertko, *Building Regulatory And Operational Flexibility Into Accountable Care Organizations and 'Shared Savings'*, 30 HEALTH AFF. 23, 25-26 (2011) (noting the needed flexibility for ACOs that can be attained through a regulatory framework).

321. RONALD A. CASS ET AL., *ADMINISTRATIVE LAW: CASES AND MATERIALS* 380 (5th ed. 2006).

322. 5 U.S.C. § 553 (2012); CASS ET AL., *supra* note 321, at 380; CMS, *Quarterly Provider Updates*, CTRS. FOR MEDICARE & MEDICAID SERVS. (May 14, 2012), <https://www.cms.gov/quarterlyproviderupdates/> [hereinafter CTRS. FOR MEDICARE & MEDICAID SERVS., *Quarterly Providers Updates*].

323. U.S.C. § 553(b); CASS ET AL., *supra* note 321, at 380; CTRS. FOR MEDICARE & MEDICAID SERVS., *Quarterly Providers Updates*, *supra* note 322.

for public comment remains open.³²⁴ In the case of COPs, CMS leaves the period open for 30 to 60 days.³²⁵ Publication of the final rule must occur at least 30 days prior to its implementation³²⁶ and include a “concise general statement of [the rule’s] basis and purpose.”³²⁷ Some have argued that this process is lengthy.³²⁸ However, this may be preferable to the legislative process where, currently, issues regarding the end of life appear to be a non-starter.³²⁹ Further, COPs are updated regularly, based on provider,³³⁰ and have been used in the past to address social issues.³³¹

COPs provide several benefits that neither a state-level nor federal legislative solution can. The goal of any proposed solution should be to encourage the conversation, not to just provide a remedy for individuals if an end-of-life conversation does not occur. Unlike a state-level solution, such as those of California and New York,³³² a change to the COP would be preemptive instead of retributive. A hospital’s noncompliance with the COPs can result in termination of the Medicare agreement with that provider.³³³ Although termination is retributive, this penalty is so severe that hospitals focus time, energy, and money to comply with the conditions of participation, making COPs essentially mandatory principles.³³⁴ Also, again, unlike the state laws, revision of the COPs creates a uniform guideline for providers.

A COP solution is also preferable to a federal legislative solution. In addition to the previously mentioned political issues, finalization of an

324. 5 U.S.C. § 553(c).

325. CASS ET AL., *supra* note 321, at 380; CTRS. FOR MEDICARE & MEDICAID SERVS., *Quarterly Providers Updates*, *supra* note 322.

326. 5 U.S.C. § 553(d).

327. *Id.* § 553(c); CASS ET AL., *supra* note 321, at 380; CTRS. FOR MEDICARE & MEDICAID SERVS., *Quarterly Providers Updates*, *supra* note 322.

328. Lieberman & Bertko, *supra* note 320, at 23.

329. Andrews, *supra* note 301.

330. See *Spotlight*, CTRS. FOR MEDICARE & MEDICAID SERVS. (Aug. 20, 2012), <https://www.cms.gov/Regulations-and-Guidance/Legislation/CFCsAndCoPs/Spotlight.html>.

331. See e.g., Alfred J. Chiplin, Jr., *Breathing Life Into Discharge Planning*, 13 ELDER L.J. 1, 31 (2005) (using conditions of participation in the discharge planning context).

332. CAL. HEALTH & SAFETY CODE § 442.5 (West 2010); N.Y. PUB. HEALTH LAW § 2997-c (McKinney 2011).

333. *Survey & Certification - Enforcement*, CTRS. FOR MEDICARE & MEDICAID SERVS. (Apr. 5, 2012), <https://www.cms.gov/SurveyCertificationEnforcement/>.

334. See, e.g., Dan M. Peterson & Melissa Thompson, *Medicare Termination: It Could Happen to You*, AHLA CONNECTIONS, Aug. 2009, at 26, available at <http://www.healthlawyers.org/News/Connections/Health%20Lawyers%20News%20Analysis/Documents/2009%20Analysis/AnalysisAug2009.pdf> (“Because of the high stakes involved, and the sometimes compressed time schedules, counsel for hospitals should understand the Medicare survey and termination process in advance, and know the strategies that work, in order to guide their clients through what can be a very difficult time.”).

agency rule takes significantly less time than finalizing a law.³³⁵ Agency flexibility and expertise are beneficial in these situations. Drafting, proposing, amending and ultimately adopting a proposed bill takes time and is often unsuccessful.³³⁶ At the agency level, experts can better evaluate the impact of a policy decision and adjust accordingly.³³⁷ For this reason, like in this case,³³⁸ Congress usually passes legislation with a broad framework while leaving the specifics to federal agencies.³³⁹ Further, CMS has already stepped into the area of the end of life with a rule requiring hospitals to maintain an advance directive policy.³⁴⁰ Hospitals must also provide written information about a patient's rights, under state law, to make "decisions concerning such medical care."³⁴¹ Therefore, CMS already has expertise and experience in promulgating rules relevant to conversations at the end of life.

CMS should revise the COPs to include a provision that specifically addresses conversations at the end of life. Section 482.13(b) sets standards for the promotion and protection of a patient's rights.³⁴² Included in the list of rights is a statement on informed consent:

The patient or his or her representative . . . has the right to make informed decisions regarding his or her care. The patient's rights include being informed of his or her health status, being involved in care planning and treatment, and being able to request or refuse treatment. This right must not be construed as a mechanism to demand the provision of treatment or services deemed medically unnecessary or inappropriate.

335. See *supra* text accompanying notes 296-304.

336. See, e.g., Kathy L. Cerminara & Seth M. Bogin, *A Paper about a Piece of Paper: Regulatory Action as the Most Effective Way to Promote Use of Physician Orders for Life-Sustaining Treatment*, 29 J. LEGAL MED. 479, 497-98 (2008) (arguing that a Physician Orders for Life-Sustaining Treatment (POLST) regulatory solution has the benefits of agency flexibility and expertise).

337. Kathleen Bawn, *Political Control Versus Expertise: Congressional Choices about Administrative Procedures*, 89 AM. POL. SCI. R. 62, 62 (1995).

338. See 42 U.S.C. § 1395x(e)(9).

339. See, e.g., Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119 (2010) (providing a loose framework while advising, in many cases, the Secretary of Health and Human Services to develop guidelines or promulgate rules); John R. Wright, *Ambiguous Statutes and Judicial Deference To Federal Agencies*, 22 J. THEORETICAL POL. 217, 217 (2010) (evaluating the judicial deference courts give administrative agencies under the *Chevron* doctrine and why Congress passes ambiguous legislation).

340. 42 C.F.R. §§ 489.100-.104 (2011).

341. 42 C.F.R. § 489.102.

342. 42 C.F.R. § 482.13(b) (2011) ("Conditions of Participation: Patient's Rights").

Despite the requirement, such behavior at the end of life is not occurring.³⁴³ However, if the provision were revised to read the following, perhaps physicians and hospitals would take this responsibility more seriously:

The patient or his or her representative . . . has the right to make informed decisions regarding his or her care. The patient's rights include being informed of his or her health status and his or her treatment options, with specific regard to those treatment options regarding end-of-life care, being involved in care planning and treatment, and being able to request or refuse treatment. This right must not be construed as a mechanism to demand the provision of treatment or services deemed medically unnecessary or inappropriate.

If the hospital were held responsible for ensuring that treatment options were provided to patients, at the very least a nurse, and very likely a physician, would speak with a patient about his or her options.

A modification of the COPs as suggested above would address several key palliative care problems. As mentioned previously, individuals using hospice either have very short or very long stays.³⁴⁴ By encouraging communication at the end of life, this regulation will likely increase the number of days individuals spend in hospice. Patients will be better informed about their disease state and healthcare providers will likely be more comfortable discussing hospice. Additionally, a regulation modification would address hospice's cherry-picking of non-cancerous residents.³⁴⁵ Not just some patients, but all, would have information about the end of life and hospice.

A modification of the COPs would be the best solution to the problem of patient-physician communication at the end of life and especially about pain medication and palliative sedation. It provides a non-retributive and unified method of pushing physicians and hospitals to do the right thing. Also, it would be more timely and flexible than a legislative solution. Further, CMS already has expertise and experience in this area.

V. CONCLUSION

Terminally ill patients have the right to be adequately informed about their palliative care treatment options, including palliative sedation. Palliative care provides caregivers and patients with an improved quality of life while reducing healthcare costs. Despite these proven benefits, people continue to suffer agonizing deaths because of failures in hospice benefits, communication, and pain management. Both California and New York

343. See *supra* Part II.B.

344. See *supra* Part II.B.

345. See *supra* Part II.B.

have addressed these deficiencies with right-to-know acts. In California, attorneys have used its Act to support a claim for elder abuse, whereas in New York, physicians may be subject to a fine or even jail time.

However, a state law solution does not seem viable. Both states' statutes have enforcement flaws. California stands alone in the strength of its elder abuse statute and *Hargett* faces serious challenges. In New York, enforcement is equally doubtful given the few number of physician public health law violations and the outrage the act has caused in the physician community. In addition, sweeping and uniform state-level change does not appear likely. Although a model uniform act has been proposed, it has not gained momentum and questions remain about how it would be modeled.

A federal solution offers the benefits of proactivity and uniformity. However, a national legislative solution is not ideal. The process to see a proposed bill through Congress can be cumbersome and wrought with political turmoil. On the other hand, amending the COPs under CMS's rulemaking authority provides needed flexibility, timeliness, and expertise. A modification of the COPs would nudge physicians in the right direction and encourage them to speak with patients about end-of-life treatment options, thus beginning to mend the broken promise of palliative care.

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