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

². R. Sean Morrison & Diane E. Meier, Palliative Care, 350 NEW ENG. J. MED. 2582, 2582 (2004).
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. The lack of satisfactory pain management is an especially disturbing area of this physician-patient disconnect. Individuals, such as members of Michelle Hargett-Beebee’s family, report seeing their loved ones dying in pain.

Two states, California and New York, have passed legislation, and others have considered legislation, 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. The more recent New York statute, as an act under the state’s Public Health Law, provides for fines and criminal penalties. However, potential problems exist at the state level. New York and California have different triggers to the physician’s duty, varied approaches to elder abuse, and the California elder abuse statute has not yet been proven to protect all patients, just a specific class. Instead, Medicare’s Conditions of Participation should require hospitals to provide terminally ill patients and their families with information about the end of life.

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. This section will also

10. See infra Part II.B.3.
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).
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.
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. Part III looks at how California and New York have approached these failures with differing state statutes and evaluates each of their shortcomings. Part IV suggests that a national standard in the form of Medicare Conditions of Participation be adopted.

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. Like a plague, it causes them to run. Instead they suggest “palliative care” for the patient. “Palliative care” does have a more benevolent tone. It sounds caring. Palliative care, from the Latin pallium, or cloak, offers patients symptom management and comfort, parallel to their curative treatment regimen. However, palliative care when someone is terminally ill is H-O-S-P-I-C-E.

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.” Then it defines and illuminates hospice explaining how hospice improves both patient and caregiver quality of life and reduces healthcare costs. 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.

A. The Promise of Palliative Care

“Palliative care is not just for the imminently dying . . . .” This common misconception often keeps patients from pursuing treatment.

23. See infra Part II.B.
24. See infra Part III.
25. See infra Part IV.
27. Id.
28. Id.
29. See id.
30. MERRIAM-WEBSTER’S COLLEGIATE DICTIONARY 893 (2009); Lamers, supra note 26, at 68.
32. See infra Part II.A.
33. See infra Part II.A.
34. See infra Part II.B.
Unfortunately, the definition of palliative care can be confusing, not just for patients, but also for academics.\textsuperscript{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.”\textsuperscript{38} Several explanatory notes including one saying palliative care “provides relief from pain and other distressing symptoms” then follow this definition.\textsuperscript{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.”\textsuperscript{40} A “disease . . . not responsive to curative treatment”\textsuperscript{41} or an illness “regardless of the prognosis”\textsuperscript{42} includes not only terminal illnesses but also chronic conditions such as heart disease, stroke, or chronic respiratory illnesses.\textsuperscript{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.\textsuperscript{44} A palliative care team is multidisciplinary and includes nurses, other medical professionals, and social workers.\textsuperscript{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.\textsuperscript{46} More than 80\% of all large hospitals have such a program.\textsuperscript{47}

Similarly confusing is what hospice is and where it fits into this conversation. Hospice, a subset of palliative care, focuses the efforts
outlined above on end-of-life care. From the Latin, hospes, meaning guest, hospice was originally provided in a facility. However, hospice currently refers to program of palliative care at the end of life provided in a multitude of settings, including the home. 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.

Many Americans depend on hospice. Almost half of all deaths in the United States occur in a hospice program. Hospice patients are predominantly white, mostly female, and overwhelmingly old. That means more than 1.5 million people depend on hospice care in this country every year. 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. However, time in hospice can be short with most patients using hospice only in their last weeks of life.

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. The most surprising finding is that palliative care may actually extend the lives of terminally ill patients. For example, a recent study of lung cancer patients found that patients who

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.
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).
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.\textsuperscript{62} Further, these patients experienced “clinically meaningful improvements in quality of life and mood.”\textsuperscript{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.\textsuperscript{64} Caregiver quality of life improves when the patient elects palliative care.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{68} Temel et al. suggest that entry into palliative care may reduce this societal and personal cost.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{72}

\textsuperscript{62} Jennifer S. Temel et al., \textit{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. \textit{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. \textit{Id.} at 735. \textit{Id.} at 739.

\textsuperscript{64} MORRISON, supra note 36, at 3.


\textsuperscript{66} \textit{Id.} at 470.

\textsuperscript{67} \textit{Id.} at 471.

\textsuperscript{68} Temel et al., supra note 62, at 740.

\textsuperscript{69} \textit{Id.}

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

\textsuperscript{71} \textit{Id.}

\textsuperscript{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. 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. 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. 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. It will then discuss the breakdown in physician-patient communication at the end of life. Finally, this section will address the importance of adequate pain management.

1. Misaligned Incentives: The Medicare Hospice Benefit

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

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. The in-patient provision of palliative care is paid for under Medicare Part A. Medicare pays hospitals a Diagnosis-Related Group (DRG) payment, essentially a flat fee, for each episode of patient care. Physicians who provide palliative care services are paid under Part B. Some physicians, specifically many hospitalists, are employed by hospitals and receive a salary or a salary with production bonuses.

The DRG system was established to incentivize reductions in hospital costs. If a hospital provides care to a patient at costs below the DRG payment, then it gets to keep the difference. Traditionally, hospitals have failed to see the promise of palliative care, especially for cutting costs. 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. 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, perhaps recognizing not just its benefit for patients but also, their bottom line.

Once a patient qualifies for hospice care, their treatment is no longer paid for under the DRG system. Payment for hospice differs from that of palliative care because Medicare has some strict requirements for qualification. 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. Medicare has covered hospice since 1982. Since then, it has become the primary source of payment for hospice services and covers the most patient days in hospice.

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. Hospice has become a place for the imminently dying. 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. In fact, the

91. Id.
94. Billings, supra note 35, at 76.
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).
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.\textsuperscript{102} Further, the lowest 25\% has actually decreased from an average stay of 6 days to just 5 days.\textsuperscript{103} The same pattern is seen at nonprofit and for-profit hospices.\textsuperscript{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.\textsuperscript{105} Hospices receive a per diem rate for services based on the location and level of care.\textsuperscript{106} They receive this daily payment no matter how many services they provide.\textsuperscript{107} Although an individual hospice is limited in the amount of Medicare payments it can receive each year,\textsuperscript{108} this does not appear to have significantly retarded the for-profit hospice industry’s growth.\textsuperscript{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\%\textsuperscript{110} and an additional 142\% between 2000 and 2009.\textsuperscript{111}

Such significant increases have led researchers to ask whether for-profit status affects quality of care.\textsuperscript{112} Whereas nonprofit hospice has emerged from a care tradition with an emphasis on “psychosocial support, spiritual
care, the use of volunteers and family, and symptom management,” for-profit care may not have the same foundation and therefore, may lack quality.\textsuperscript{113} However, studies have been rare and inconsistent.\textsuperscript{114} One 2004 study did conclude that patients in for-profit hospice were receiving fewer non-core services than patients in nonprofit hospice settings.\textsuperscript{115} Others have shown that in a for-profit facility, there is less skilled nursing care\textsuperscript{116} and fewer interdisciplinary staff.\textsuperscript{117}

Next, evidence suggests that hospices may be “cherry-picking” residents.\textsuperscript{118} Cherry-picking refers to the practice of choosing only those most desirable patients.\textsuperscript{119} For instance, the Medicare benefit’s per diem structure incentivizes recruiting patients likely to live longer while needing fewer services.\textsuperscript{120} According to MedPAC, very long stays have grown from an average of 141 days to an average of 237 days.\textsuperscript{121} Although “counterintuitive,” longer stays actually are more profitable because of the U-shaped curve of the cost of providing hospice care.\textsuperscript{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.\textsuperscript{123} Therefore, the longer a patient stays in hospice care, the longer the period of profit at the bottom of the U-curve.\textsuperscript{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

\begin{itemize}
  \item \textsuperscript{113} Id. at 437.
  \item \textsuperscript{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. \textit{Id.} at 432.
  \item \textsuperscript{115} \textit{Id.} at 435. Core services must be provided by the hospice organization at all times. \textit{CTS. 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. \textit{Id.} at 40.5. Non-core services must be provided to meet the patients’ and families’ needs. \textit{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. \textit{Id.}
  \item \textsuperscript{116} Perry & Stone, supra note 105, at 230.
  \item \textsuperscript{117} \textit{Id.}
  \item \textsuperscript{118} See \textit{id.} at 228.
  \item \textsuperscript{119} Stephanie Bouchard, Concerns Raised About Increase in For-Profit Hospice Care, \textit{HEALTHCARE FIN. NEWS} (May 26, 2011), http://www.healthcarefinancenews.com/news/concerns-raised-about-increase-profit-hospice-care.
  \item \textsuperscript{120} Perry & Stone, supra note 105, at 229.
  \item \textsuperscript{121} \textit{MEDICARE PAYMENT ADVISORY COM’N}, supra note 52, at 269.
  \item \textsuperscript{122} Perry & Stone, supra note 105, at 228.
  \item \textsuperscript{123} \textit{Id.}
  \item \textsuperscript{124} \textit{Id.} at 228-29.
\end{itemize}
Furthermore, patients in for-profit hospices are more likely to stay longer than a year in hospice. The fact that for-profit hospice tends to generate more revenue than nonprofit hospice can be attributed to cherry-picking longer-stay patients.

An extension of this analysis provides an explanation for for-profit hospices’ exclusion of cancerous patients, perhaps this rationale’s most detrimental effect. 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.

Their study found that not only were for-profit hospices selecting non-cancerous patients, but also were specifically selecting dementia patients. 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. Further, dementia patients have significantly longer stays than all other patient types.

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.nhpco.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

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134. See id.


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).


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. Similarly, national standards for patients with incurable cancer recommend that these conversations occur when a patient’s life expectancy falls to within one year.

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. When they do occur, they take place, on average, just a month prior to death in the hospital setting. Even when a physician shares information with a patient, there is no guarantee the information has been understood. 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. 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.”

Physicians acknowledge that these discussions at the end of a patient’s life cause uncertainty and apprehension. Emotionally, the physician may feel helpless or like she is failing the patient. 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.” Further, in the so-called “hidden curriculum,” physicians may be taught to be dismissive or even avoidant of palliative care.

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.
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.
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

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.\textsuperscript{161} The SUPPORT study concluded that those with colon cancer reported more pain than patients with other disease types.\textsuperscript{162} Cancer patients, therefore, may have different pain medication needs than those with other illnesses.\textsuperscript{163} The wide variance of pain experiences among patients and its clear undertreatment underscore the importance of asking patients about their pain.\textsuperscript{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.\textsuperscript{165} Physician pain management training is woefully inadequate,\textsuperscript{166} and perhaps this leads to patients receiving little or no information about medication.\textsuperscript{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.\textsuperscript{168} Physicians also worry about patient addiction.\textsuperscript{169} Similarly, patients’ own fears of addiction may contribute to this misperception.\textsuperscript{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.\textsuperscript{171} Under palliative sedation, a patient can be rendered completely unconscious.\textsuperscript{172} The scientific community continues to debate when sedation is appropriate.\textsuperscript{173} Of specific concern is how close to death a patient needs to be in order to receive this treatment.\textsuperscript{174} Some physicians argue that the line

\begin{itemize}
\item See id.\
\item Id.\
\item Id. at 1960.\
\item See Rima J. Oken, Curing Healthcare Providers’ Failure to Administer Opioids in the Treatment of Severe Pain, 23 CARDozo L. REV. 1917, 1933 (2002).\
\item Id. at 1933-34.\
\item See Furrow, supra note 155, at 28.\
\item Id.\
\item 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).\
\item Furrow, supra note 155, at 28.\
\item Jeffrey T. Berger, Rethinking Guidelines for the Use of Palliative Sedation, HASTINGS CENTER REP., May-June 2010, at 32, 33.\
\item Id. at 32-33.\
\item Id. at 33.\
\item Id.\
\end{itemize}
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.\textsuperscript{175} A great deal of this concern stems from the fact that palliative sedation can hasten a person’s death.\textsuperscript{176} However, palliative sedation is recognized as a patient’s right even if it does accelerate death\textsuperscript{177} and most individuals under palliative sedation die from the underlying illness, not the medication.\textsuperscript{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.\textsuperscript{179} His wife and son could no longer take care of him at home because of his erratic behavior.\textsuperscript{180} Once in the hospice center, physicians, with the support of his family, decided to provide his pain medication intravenously.\textsuperscript{181} His erratic behavior stopped and Mr. Oltzik appeared at peace.\textsuperscript{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.\textsuperscript{183} Ultimately his wife decided against insertion of a tube.\textsuperscript{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.\textsuperscript{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

\textsuperscript{175}. Id.

\textsuperscript{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.

\textsuperscript{177}. See, e.g., Washington v. Glucksberg, 521 U.S. 702, 737-38 (1997) (O’Conner, 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.”).

\textsuperscript{178}. Berger, supra note 171, at 33.

\textsuperscript{179}. Hartocollis, supra note 73.

\textsuperscript{180}. Id.

\textsuperscript{181}. Id.

\textsuperscript{182}. Id.

\textsuperscript{183}. Id.

\textsuperscript{184}. Hartocollis, supra note 73.

\textsuperscript{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).
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.
190. See infra Part III.B.
In 2008, California Governor Arnold Schwarzenegger signed into law the Right to Know End-of-Life Options Act (Right to Know Act). Advocates saw this as a victory for patients, while medical professionals scoffed at the legislature’s interference into their realm. 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.

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. In prior years, more expansive legislation allowed Californians to request medication to “provide comfort with an assurance of peaceful dying if suffering becomes unbearable.” 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.

195. The vote was 42-34 with all the Republican House members, joined by two Democrats, voting against the measure. Russo, supra note 191.
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. One commentator noted that this was in fact a “modest measure dealing only with a patient’s right to be informed.”

The first of its kind, 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.” 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.

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

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.” 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.” Assuming that this language is applicable, physicians are given more time than with the Medicare hospice benefit. However, similar to the Medicare benefit, such timelines create a lot of uncertainty on the part of the physician. 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.”


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.
Despite the California Medical Association’s (CMA) support for the measure, physicians still express concern that the law “unduly interferes with the physician-patient relationship.” Specifically, they argue that such legislation may result in “information dumping.” Such information overload, physicians fear, would preclude them from having detailed conversations with patients at the appropriate times. 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.”

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. Michelle, a young mother, had died agonizingly in the care of a large for-profit hospice, Vitas. The hospice staff was aware from early on that Ms. Hargett-Beebee was suffering and failed to adequately address her pain. In 2010, Compassion & Choices filed suit against Vitas under an elder abuse theory. 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).

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

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).
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. Id. § 15657.
225. Id. § 15610.57.
226. Id. § 15657.
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. In 1998, William Bergman, 85 years old, against his wish to die in peace, died in agony. 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. Mr. Bergman’s lung cancer had spread, causing his bones to fracture. Over the next six days, he rated his pain from 7 up to 10 on a 10-point scale, indicating moderate to severe pain. His family notified physicians but little to no action was taken. He died three days later at home.

His daughter subsequently reached out to a California nonprofit advocacy group, Compassion & Choices, for help filing suit. They filed an elder abuse case against Dr. Chin, the treating physician. Specifically, the plaintiff argued that Dr. Chin had been reckless when he neglected to establish a regimented pain management program for Mr. Bergman.

The Bergman jury found Dr. Chin had committed reckless neglect when he failed to adequately treat Mr. Bergman’s pain. 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). Therefore, although heightened remedies may be available in an elder abuse claim against a medical professional, they were not applied here. 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.


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, a duty that has already been established under informed consent. By strengthening the physician’s duty, plaintiffs hope to make a case for recklessness. 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.

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). Heralded as an “important step” to encourage trust and communication between patients and physicians, PCIA also requires physicians to discuss end-of-life options with terminally ill patients. 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.
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.” Unlike the California statute, PCIA does not specifically list areas to be discussed. 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.” Similar to the California statute, physicians still consider this terminal illness language to be too forceful given the uncertainty in accurate prognostication of death.

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. 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.” In contrast, the California act specifically requires “upon request” that physicians fully inform terminal patients about their options. This is a “conditional duty,” a “duty that is conditioned on the occurrence of an event other than the lapse of time.” 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. In order for a duty to arise for the physician, the patient must first specifically ask for the information. No such condition is required by the New York statute.

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. Some controversy surrounds the impression that the statute itself contains the monetary and jail time penalties. 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. 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).
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.
260. CAL. HEALTH & SAFETY CODE § 442.5.
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.\textsuperscript{265} The Right to Know Act’s codification does not include a penalty for violations.\textsuperscript{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.\textsuperscript{267} Like the California elder abuse law, more than mere negligence is required.\textsuperscript{268} “Willful” is defined as a deliberate and voluntary action.\textsuperscript{269} Physicians have been convicted of willfully neglecting their patients under the public health laws of New York.\textsuperscript{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.\textsuperscript{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,\textsuperscript{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

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

\textsuperscript{266} Id. § 442.5.

\textsuperscript{267} \textit{N.Y. PUB. HEALTH LAW} §§ 12, 12-b.


\textsuperscript{269} Id.

\textsuperscript{270} See, e.g., \textit{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); \textit{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).

\textsuperscript{271} Using Westlaw, I reviewed cases referencing \textit{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.

\textsuperscript{272} See, e.g., \textit{Astrow & Popp}, supra note 254, at 1885.
laws in the country, New York does not have a similar civil statute. 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. 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, evidence suggests that pain management medical malpractice cases can be hard to prove given differing pain management standards.

California’s Right to Know Act will also face enforcement challenges. Although California has a stronger elder abuse framework than New York, this enforcement strategy has several flaws. First, heightened remedies are only afforded to those cases in which “recklessness” can be proved. 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.” Although Bergman established that this “recklessness” standard could apply to inadequate pain management, neither Delany nor Bergman establishes where the line between professional negligence and reckless neglect can be drawn.

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

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.
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.
279. CAL. WELF. & INST. CODE § 15657.
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).
who may be covered by the elder abuse statute.\textsuperscript{284} Ms. Hargett-Beebee was not an elder adult.\textsuperscript{285} Instead, the plaintiffs are arguing she was a “dependent adult” because of her physical illness at the end of life.\textsuperscript{286} However, Ms. Hargett-Beebee may not fall under the elder abuse statute’s definition.\textsuperscript{287} Relying on the statute’s legislative intent,\textsuperscript{288} the defendants in the Hargett case argue that her inclusion may implicate the inclusion of every individual at the end of life.\textsuperscript{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.\textsuperscript{290} Further, if the Hargett theory does prevail, damages could be limited as they were in the Bergman case.\textsuperscript{291}

Currently, California and New York are the only states that have explicit right to know laws.\textsuperscript{292} Several states have introduced some form of a right to know bill with varied success.\textsuperscript{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


\textsuperscript{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.”).

\textsuperscript{287} CAL. WELF. & INST. CODE § 15610.23.

\textsuperscript{288} Defendants’ Demurrer, supra note 284, at 5.

\textsuperscript{289} Id.

\textsuperscript{290} Defendants have attempted to make this argument, though a court has yet to decide on it. Id.

\textsuperscript{291} Mayer, supra note 221, at 342.

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

\textsuperscript{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!).
A proposal has been introduced to the Uniform Law Commission’s Committee on Scope and Program\textsuperscript{295} recommending that a uniform state statute requiring conversations at the end of life be promulgated.\textsuperscript{296} The uniform law theory has not picked up steam, as the most recent petition was denied.\textsuperscript{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,\textsuperscript{298} the California statute does not.\textsuperscript{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.\textsuperscript{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.\textsuperscript{301} Fears of “death panels” and “pull the plug on Grandma” effectively quashed earlier versions of the Affordable Care Act.\textsuperscript{302} Although Section 1233 of H.R. 3200, an “advance planning consultation” provided for just that, a conversation,\textsuperscript{303} fears of

\textsuperscript{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. \textit{About the ULC}, UNIF. LAW COMM’N (2012), http://uniformlaws.org/Narrative.aspx?title=About the ULC.

\textsuperscript{295} The Committee on Scope and Program is responsible for setting the commission’s agenda. \textit{Types of Committees}, UNIF. LAW COMM’N (2012), http://uniformlaws.org/Narrative.aspx?title=Types of Committees.


\textsuperscript{297} \textit{Id.}

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

\textsuperscript{299} \textit{CAL. HEALTH & SAFETY CODE} § 442.5 (West 2010).

\textsuperscript{300} \textit{Id.;} N.Y. PUB. HEALTH LAW § 2997-c.


\textsuperscript{302} \textit{Id.}

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’s 307 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

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 hospital services, outpatient diagnostic services, outpatient physical, occupational and speech therapy and more). For a complete list see id. at 543-44.
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 COPs while state survey agencies review hospital compliance. A hospital may be removed from a state survey agency’s list if the Joint Commission or the American Osteopathic Association accredits it. No matter the path, a hospital must meet or exceed the COPs in order to receive Medicare reimbursement.

Although conditions of participation are required for all healthcare facilities, excluding nursing homes, 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. Additionally, hospital conditions of participation include hospital outpatient services. The reach of hospital COPs may increase with the advent of the Accountable Care Organization. COPs for these increasingly integrated organizations, which may include linked physician groups and hospitals, will likely be similar to those for hospitals.

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


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.


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).


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

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, 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. 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. 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.
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).
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%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).
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).
341. 42 C.F.R. § 489.102.
Despite the requirement, such behavior at the end of life is not occurring. 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. 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. 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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* Katherine B. Ledden is a 2013 Saint Louis University J.D./M.P.H.-Health Policy candidate. Special thanks to Professor Kathy Cerminara for imparting a small portion of her great wisdom and a ton of guidance. Also, thank you to my partner in crime, Nicholas Ledden, for his support and patience. I dedicate this piece to my mother, without whom I would have never had the courage to face the end of life.