

# Changing the Means to Justify the End: Recommendations for the New York Palliative Care Information Act

ABIGAIL M. LOWIN\*

*Advance care-planning conversations give health care providers and patients the opportunity to discuss the patient's future "goals of care." Currently, only a small proportion of physicians hold such conversations. Statutes in New York, Michigan, California, and Vermont require certain practitioners to hold these conversations with terminally ill patients. Failure to comply is considered a misdemeanor. The purpose of this Note is to elucidate how these statutes might be read in different healthcare contexts and what practical consequences may ensue for both patient and practitioner. The Note closely examines these four right-to-know statutes, drawing on legislative history, activist input, and empirical research to predict the potential outcomes of the statutory language in each state. The Note highlights the merits and obstacles presented by each state's statute and culminates with advice for lawmakers and physicians in New York State looking to maximize the potential benefits available under New York's law, based on lessons learned from the other states' statutes.*

## I. INTRODUCTION

Advance care-planning is a process of ongoing conversations between a physician and his patient, during which the involved parties determine the patient's "goals of care" and how the physician can best achieve those goals, through a balance of curative

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\* Executive Notes Editor, Colum. J.L. & Soc. Probs., 2015–2016. J.D. Candidate 2016, Columbia Law School. The author would like to thank Professor Peter Strauss for his invaluable insight and advice, and the editorial staff of the *Columbia Journal of Law & Social Problems* for their wonderful support throughout the editing process. She also thanks Professor James Colgrove for his flexibility and encouragement while overseeing her Master's thesis, which formed the basis for this Note.

and palliative care.<sup>1</sup> To counsel his patient effectively on palliative and end-of-life care options,<sup>2</sup> a practitioner must personalize his provision of end-of-life care information to his patient's individual ability to receive that information. The practitioner must also be certain that the recipient of his guidance has both the mental and legal capacity to understand and process it.<sup>3</sup>

Most states have legislation specifying the identities of parties who must or may be involved in advance care-planning.<sup>4</sup> New York, Michigan, Vermont, and California build on that foundation by also controlling the topics that practitioners can or must address, as well as the circumstances or manner in which they

1. A rather comprehensive explanation of advance care-planning and its goals can be found in Paul V. Aitken, *Incorporating Advance Care Planning into Family Practice*, 59 AM. FAM. PHYSICIAN 605, 607 (1999) (citing Joan M. Teno et al., *Advance Care Planning Priorities for Ethical and Empirical Research*, 24 THE HASTINGS CENTER REP. S32, S33 (1994)). These goals are summarized as the following:

1. Ensure that clinical care is in keeping with the patient's preferences when the patient has become incapable of decision making.
2. Improve the health care decision-making process.
  - a. Facilitate a shared decision-making process among the patient, physician and proxy, guided by the patient's preferences.
  - b. Allow the proxy to speak on behalf of the patient.
  - c. Respond with measured flexibility to unforeseen clinical situations.
  - d. Provide education regarding the issues that surround death and dying.
3. Improve patient outcome.
  - a. Improve the patient's well-being by reducing the frequency of over-treatment and undertreatment.
  - b. Reduce the patient's concerns regarding the possible burden placed on family and significant other people.

Palliative care, one of the topics generally covered during advance care-planning, is also called "comfort care" or "pain management." This Note employs the definition introduced to the New York State Assembly in 2014, and again in 2015, meant to standardize the definition throughout the state's public health law: "Palliative care' means health care treatment, including interdisciplinary end-of-life care, consultation with patients and family members, and psychosocial and spiritual support, to prevent or relieve pain and suffering and to enhance the patient's quality of life." A.B. 2211, 2015 Leg., 238th Sess. (N.Y. 2015); S.B. 7504, 2014 Leg., 237th Sess., (N.Y. 2014).

2. Palliative care is often confused with "hospice care," which is intended for patients who have agreed to forego curative treatments with an eye toward a peaceful, comfortable death. In contrast, physicians may administer palliative care to a patient alongside curative care, giving the appearance of solely curative care.

3. For a discussion of the different standards for determining "mental capacity" and "legal competence," see Alec Buchanan, *Mental Capacity, Legal Competence and Consent to Treatment*, 97 J. R. SOC. MED. 415 (2004) ("The law recognizes that mental capacity is a continuous quality that may be present to a greater or lesser extent. Legal competence, however, cannot be. . . . A person is either entitled or not entitled, at law, to have their wishes respected regarding treatment.").

4. See generally COMMISSION ON LAW AND AGING, AMERICAN BAR ASSOCIATION, HEALTH CARE DECISION MAKING AUTHORITY: WHO MAKES THE DECISION? (2015), [http://www.americanbar.org/content/dam/aba/administrative/law\\_aging/Who\\_Makes\\_the\\_Decision.authcheckdam.pdf](http://www.americanbar.org/content/dam/aba/administrative/law_aging/Who_Makes_the_Decision.authcheckdam.pdf) [<http://perma.cc/5QU4-BMA8>].

must do so. However, each of these four states does so in a unique way, and comparing those methods can provide insight into best practices.

The purpose of this Note is to compare the text and legislative history of right-to-know statutes regarding palliative-care options in New York, Michigan, California, and Vermont, in order best to inform practitioners, their attorneys, and lawmakers regarding practical outcomes and constructive amendments to New York's Palliative Care Information Act. Part II examines the historical and cultural context of advance care-planning in the United States to explain the roots of the problem of inadequate advance care-planning and the states' need for these informed-consent statutes. Parts III and IV analyze and compare three main aspects of these laws: which practitioners and patients, or patient-representatives, are governed by the respective statutes; what topics they must address under the statute, and in what manner; and the disciplinary or enforcement actions available to ensure practitioner compliance with the laws. Part III focuses on these aspects of New York's law, while Part IV revolves around the palliative-care informed-consent laws of Michigan, California, and Vermont, contrasting them with New York's statute where applicable. Part V contains recommendations for ways to improve New York's current law based on current practices in Michigan. These proposed amendments include an improved evidentiary standard that could protect both patients and practitioners, and disciplinary actions more specifically tailored to the Palliative Care Information Act.

## II. BACKGROUND AND LEGAL CONTEXT

The term "advance care-planning" suggests some type of communication, usually through oral conversations, about the care a particular patient would like to receive in the future. The exact definition may vary depending on who is using the term, and in what context.<sup>5</sup> This Part outlines the significant role that advance care-planning can play in improving patients' well-being and the hurdles that advocates for the practice have encountered in the United States.

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5. See Charles P. Sabatino, *Advance Care Planning in a Nutshell*, 35 BIFOCAL 151, 152 (2014) (describing the different forms advance care-planning can take).

The process of ongoing conversations between patient and provider can both give the patient peace of mind and provide guidance for the practitioner and the patient's representative, sometimes called a "surrogate," who may be entitled under law to make medical decisions on the patient's behalf. The conversations might emerge as part of an annual check-up or revolve around a particular diagnosis.

Advance care-planning ideally occurs throughout a patient's lifetime, since illness and accidents can strike at any age. This Note focuses more narrowly on the role of advance care-planning in the context of terminal illness, since most state legislation on this topic is tailored specifically to terminally ill patients. Advance care-planning generally occurs between a physician and his patient, rather than between a social worker or attorney and their clients, because, in the United States, end-of-life care is a health care issue.<sup>6</sup>

#### A. SIGNIFICANCE AND CULTURAL CONTEXT OF ADVANCE CARE-PLANNING

Advance care-planning is about more than just succinct, one-time instructions for acute end-of-life care. It is ideally an ongoing dialogue that includes a more generalized attempt to understand the patient's "goals of care."<sup>7</sup> It does not require any sort of medical or legal expertise; indeed, while the planning often starts in a physician's office, individuals can develop and record their plans without help or input from any professional.<sup>8</sup> Because the dialogue is based purely on conversations rather than screenings, blood tests, and surgeries, health insurance providers historically have not reimbursed physicians for such conversations. However,

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6. See U.S. Dep't of Health and Hum. Servs., *Literature Review on Advance Directives*, 1, 36 (June 2007) (noting that 80% of deaths in the United States occur in health-care settings, so that even when social workers or non-medically trained individuals are involved in the advance care-planning process, that involvement occurs within the context of health care facilities, such as the Veteran's Health Administration outpatient clinics); but see Charles P. Sabatino, *The Evolution of Health Care Advance Planning Law and Policy*, 88 THE MILBANK Q. 211 (exploring the statutory history of advance directives, living wills, and other documents relevant to terminal illness as the basis for attorney involvement in a terminally ill individual's planning process).

7. See Aitken, *supra* note 1.

8. See generally COMMISSION ON LAW AND AGING, AM. BAR ASS' N, HEALTH DECISIONS RESOURCES (2015), [http://www.americanbar.org/content/dam/aba/administrative/law\\_aging/Health\\_Decisions\\_Resources.authcheckdam.pdf](http://www.americanbar.org/content/dam/aba/administrative/law_aging/Health_Decisions_Resources.authcheckdam.pdf) [<http://perma.cc/UQ27-X2QL>].

mounting national attention has recently led some insurers to begin covering these conversations for certain populations.<sup>9</sup>

Through the ongoing process of advance care-planning, a patient can lay out for his current and future caretakers any level of specificity regarding the care he would like to receive, from vague, essentially unproductive, generalities (“Do not resuscitate if my prognosis is bad.”) to specific directives (“Withdraw all curative treatments and initiate solely palliative care on my 90<sup>th</sup> birthday.”).

The patient’s life stage and prognosis are usually key factors in the type of conversation and resulting directive. For example, an Alzheimer’s patient, often unaware of the extent of her disease until it is too late to make decisions, may want to let the Alzheimer’s take its course, since there is no proven cure. An individual experiencing acute kidney failure may have witnessed a friend endure countless painful intubations, and is therefore averse to the idea of dialysis treatments. A patient with a recent pancreatic-cancer diagnosis, on the other hand, may have friends with similar histories who have defied statistics and lived for years beyond the diagnosis, and is thus eager to learn which treatments can do the same for him. These three scenarios are representative of the types of circumstances in which a patient would want to engage in advance care-planning, if only the practitioner could reliably introduce the topic in a comfortable, informative way.

The most significant barrier to effective advance care-planning is the American cultural attitude — usually one of aversion — toward the topics of death and dying.<sup>10</sup> This fear was amplified

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9. See, e.g., EMPIRE BLUECROSS, FREQUENTLY USED CPT II CODES FOR MEDICARE ADVANTAGE (2013), available at [http://www.empireblue.com/shared/noapplication/f2/s2/t1/pw\\_e196445.pdf?refer=ehpmedicare](http://www.empireblue.com/shared/noapplication/f2/s2/t1/pw_e196445.pdf?refer=ehpmedicare) [<http://perma.cc/W5V4-ZMR3>] (listing “advance care planning” as a Current Procedural Terminology (CPT) II code under the metric of “Care for Older Adults”). As of Jan. 25, 2016, the Centers for Medicare and Medicaid Services (CMS) had published a final rule with comment period, that included a CPT reimbursement code for physicians holding advance care-planning conversations with their patients. In calendar year (CY) 2015, the code was listed as “Inactive,” but for CY 2016, CMS changed this indication to “Active,” meaning that physicians may use the reimbursement code, but must check with their local standards rather than a national Medicare standard. Medicare Program; Revisions to Payment Policies under the Physician Fee Schedule and Other Revisions to Part B for CY 2016. 80 Fed. Reg. 70,886, 70,888 (published Nov. 16, 2015) (to be codified at 42 C.F.R. pt. 405).

10. See, e.g., ELIZABETH KÜBLER-ROSS, ON DEATH AND DYING: WHAT THE DYING HAVE TO TEACH DOCTORS, NURSES, CLERGY, AND THEIR OWN FAMILIES 28 (1969) (“If denial is no longer possible, we can attempt to master death by challenging it.”); IRA S. BYOCK,

during the debates leading up to the passage of the 2010 Affordable Care Act,<sup>11</sup> which was to include a provision authorizing Medicare to reimburse physicians for advance care-planning conversations once every five years.<sup>12</sup> New York's former Lieutenant Governor Betsy McCaughey opened a toxic can of worms when she began a rumor that the federal government was planning to "tell [patients] . . . how to end their lives sooner," and she argued that "government should have nothing to do" with the "sacred issues of life and death."<sup>13</sup> Alaskan Governor and one-time vice presidential candidate Sarah Palin then introduced the term "death panels."<sup>14</sup> Succumbing to the political pressure following this cascade of misinformation, the Affordable Care Act that President Obama signed into law months later conspicuously lacked any mention of advance care-planning beyond a vague ed-

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M.D., DYING WELL: PEACE AND POSSIBILITIES AT THE END OF LIFE 241–42, 246 (The Berkeley Publishing Group, 1st ed. 1998) ("People fear tangible things related to when and how they will eventually die: being abandoned; becoming undignified in terms of what they do, how they look, and how they smell; being a burden to their families . . . dying in pain. . . . To make matters worse, the current health care crisis has caused many people to be pauperized simply because of being incurably ill and not dying quickly enough. . . . When help is given by society, it is begrudgingly. . . . Cultural values and expectations related to dying must shift away from the denial of death, and the viewing of dying as a time of inevitable emotional distress and barely avoidable physical suffering, toward an understanding of dying as a part of full, even healthy, living, and toward accepting care for the dying as a valuable part of the life of the community."). Little has changed over the last several decades in the American mindset toward death. See, e.g., Thomas J. Smith & Dan L. Longo, *Talking with Patients About Dying*, 367 NEW ENG. J. MED. 1651 (2012) (emphasizing patients' ongoing unconscious efforts at self-deception when discussing mortality).

11. Patient Protection and Affordable Care Act of 2010, Pub. L. No. 111-148, 124 Stat. 119 (2010).

12. America's Affordable Health Choices Act of 2009, H.R. 3200, 111th Cong. § 1233 (2009) (including detailed information on what an "advance care-planning consultation" would look like, how the corresponding "physician quality reporting system" would work, and how to explain such a consultation in the Medicare & You handbook sent to every Medicare beneficiary).

13. Brendan Nyhan, *Why the 'Death Panel' Myth Won't Die: Misinformation in the Health Care Reform Debate*, 8 THE FORUM 1, 8 (2010) (discussing McCaughey's increasing role during the Clinton and Obama administrations in espousing falsehoods related to their health care policies and legislation).

14. *Id.* at 1, 10 (quoting Palin's now-defunct post on Facebook). Actually, the public misunderstood Palin's comments, which were not about advance care-planning (though the public, and she, eventually used "death panel" to refer to those conversations) but rather about a fictitious provision that authorized a committee of bureaucrats to decide if a "sick, elderly, or disabled" individual was "worthy of healthcare." In fact, the panel to which Palin was referring does exist, albeit in more practical and less fatalistic form, and is known as the Independent Payment Advisory Board (IPAB). See *id.* (citing Palin's now-defunct Facebook post); Pub. L. No. 111-148, Title III, § 3403(a)(1), 124 Stat. 489 (codified at 42 U.S.C.A. 1395kkk (West 2015) (IPAB's purpose is to "reduce the per capita rate of growth in Medicare spending.")).

education and counseling requirement in Medicare beneficiaries' "Initial Preventive Physical Examination."<sup>15</sup>

This aversion to discussing death also plagues health care practitioners — professionals who are meant to care for and support patients through the transition from life to death. Generally, neither medical schools nor residency programs adequately prepare future physicians for such weighty assessments and conversations.<sup>16</sup> The lack of education for medical leaders translates into both a cause and a result of the American aversion to discussing death and dying. One study found that while 80% of physician respondents felt positively toward their patients' completion of advance directive documents, only 55% had ever engaged in the key accompanying conversations.<sup>17</sup> The quality of advance care-planning conversations across the nation has hardly improved, and as a result, patients are suffering at the hands of those who are meant to help them.<sup>18</sup> Patients rely on their doctors for complete, honest communication, but one study found that only two-thirds of doctors told their patients that their illnesses were incurable, and only about a third ever communicated the patient's true prognosis.<sup>19</sup>

The consequence of such an aversion to acknowledging the possibility of mortality is that the United States continues to see a troublingly low rate for recording patient preferences, whether through formal documentation or physician notes on advance

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15. CENTERS FOR MEDICARE & MEDICAID SERVICES, QUICK REFERENCE INFORMATION: THE ABCS OF PROVIDING THE INITIAL PREVENTIVE PHYSICAL EXAMINATION (IPPE) (2015), [http://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/downloads/MPS\\_QRI\\_IPPE001a.pdf](http://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/downloads/MPS_QRI_IPPE001a.pdf) [<https://perma.cc/DX9V-D3KW>].

16. Renee Pekmezaris et al., *The Impact of an End-of-Life Communication Skills Intervention on Physicians-in-Training*, 32 GERONTOLOGY & GERIATRICS ED. 152, 152–53 (2011) (“[R]esidents consistently report lack of knowledge in managing end-of-life decision making.”).

17. Kent W. Davidson et al., *Physicians' Attitudes on Advance Directives*, 262 JAMA 2415 (1989). *But see* COMMISSION ON LAW AND AGING, *supra* note 8 (noting that expert input is not wholly necessary for advance care-planning to occur; however, this professional assistance can greatly facilitate the process for individuals unfamiliar with the territory).

18. *See* Pekmezaris et al., *supra* note 16, at 153 (“79% of physicians surveyed believe that they need additional training in end-of-life skills.”) (citing Larrie W. Greenberg et al., *Communicating Bad News: A Pediatric Department's Evaluation of a Simulated Intervention*, 103 PEDIATRICS 1210 (1999)). One British survey demonstrated that the aversion to advance care-planning is more than a solely American idiosyncrasy. Jacqui Wise, *Dying Remains a Taboo Subject for Patients and GPs, Finds Survey*, 344 BMJ e3356 (2012), <http://dx.doi.org/10.1136/bmj.e3356> [<http://perma.cc/Q55L-ZQ74>].

19. Smith & Longo, *supra* note 10, at 1652 (alluding to the poor state of communication that currently exists between physicians and their patients).

care-planning conversations. According to a 2008 Congressional report, only 18–36% of Americans had documented advance directives in a formal, written manner.<sup>20</sup> This figure was only slightly higher when applied to individuals with serious illnesses, a group for whom advance care-planning and accompanying legal documents are paramount in determining short- and long-term care plans.<sup>21</sup> A more recent study in Maryland noted the state’s continually low rate of reported or documented conversations, despite over 60% of survey respondents reporting that they did have certain preferences for their end-of-life care.<sup>22</sup> Research into advance-directive completion rates has documented the extreme financial burden placed on patients and their families who do not plan ahead for appropriate end-of-life care,<sup>23</sup> and the undue emotional distress experienced by all parties involved in those cases.<sup>24</sup>

Most states impose no additional requirements on the physician-patient relationship than the generally accepted standards set forth by the American Medical Association. However, some have stepped in to mandate certain behaviors and activities, particularly when it comes to advance care-planning. New York, for example, requires physicians to counsel terminal patients on var-

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20. U.S. DEP’T HEALTH AND HUM. SERVS., ADVANCE DIRECTIVES AND ADVANCE CARE PLANNING: REPORT TO CONGRESS, x (2008).

21. *Id.*

22. Keshia M. Pollack et al., *The Public’s Perspectives on Advance Directives: Implications for State Legislative and Regulatory Policy*, 96 HEALTH POL’Y 57, 61 (2010).

23. Baohui Zhang et al., *Health Care Costs in the Last Week of Life: Association with End-of-Life Conversations*, 169 ARCHIVES OF INTERNAL MED. 480, 484 (2009) (“Our findings demonstrate that advanced cancer patients who reported EOL conversations with physicians had lower medical costs in their final week of life compared to those who did not, which is largely a function of their more limited use of intensive interventions.”); Samuel Marshall et al., *The Risk of Out-of-Pocket Health Care Expenditure at End of Life* 1–3 (Nat’l Bureau of Econ. Research, Working Paper No. 16,170, 2010), <http://www.nber.org/papers/w16170.pdf> [<http://perma.cc/YUN7-X9YN>] (comparing past research demonstrating average health care spending of \$2500 for individuals not near death, with original data that those in the last year of life reported average spending of \$11,618, the 90<sup>th</sup> percentile equal to \$29,335, and the 99<sup>th</sup> percentile equal to \$94,310) (citing Kathleen McGarry & Robert Schoeni, *Medicare Gaps and Widow Poverty*, 66 SOC. SEC. BULL. 58, 72 (2005)).

24. Alexi A. Wright et al., *Associations Between End-of-Life Discussions, Patient Mental Health, Medical Care Near Death, and Caregiver Bereavement Adjustment*, 300 JAMA 1665, 1668 (2008) (“Patients who received aggressive medical interventions had worse quality of life in the final week of life.”); Mary Thelen, *End-of-Life Decision Making in Intensive Care*, 25 CRITICAL CARE NURSE 28, 34 (2005) (“Family members described making these [end-of-life] decisions for patients as work that was ‘overwhelming’ and ‘devastating.’”) (citing Virginia P. Tilden et al., *Family Decision Making in Foregoing Life-Extending Treatments*, 5 J. FAM. NURSING 426, 435 (1999)).



ious end-of-life care options, although the effectiveness of that requirement has been limited because the state has failed to mandate sufficient physician education on the topic.<sup>25</sup> Other state laws addressing physician-patient conversations vary — from California’s general instruction that physicians need discuss end-of-life care only upon patient request to Florida’s outright restriction of physician speech on certain topics altogether.<sup>26</sup>

Understandably, practitioners resent this intrusion on their practice. One strong coalition of practitioners has protested that, contrary to the laws’ alleged goals, legislative mandates “devalue the patient-physician relationship” and ignore the fact that practitioners are already held to the high standards of “autonomy, beneficence, nonmaleficence, and justice.”<sup>27</sup> In reality, practitioners who practice and hold by all of those standards in every patient action have no need for concern, because these laws should simply reaffirm those four standards. Common sense dictates that the idea of informed consent, which subsumes all of those standards, translates to a practitioner’s presentation of all reasonable therapies available and appropriate to his patient, including palliative care.<sup>28</sup> Yet statistics clearly show that not all practitioners explain the full details of their patients’ conditions,

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25. Palliative Care Information Act, N.Y. PUB. HEALTH LAW § 2997-c(2) (McKinney 2010) (“If a patient is diagnosed with a terminal illness or condition, the patient’s attending health care practitioner shall offer to provide the patient with: (a) information and counseling regarding palliative care and end-of-life options . . .”). See *infra* Part II.A.

26. CAL. HEALTH & SAFETY CODE § 442.5(a)(2) (West 2015) (“Upon the request of the patient . . . provide the patient or other authorized person with comprehensive information and counseling . . .”); FLA. STAT. ANN. § 790.338(1)–(2) (West 2011) (Aimed at reducing discrimination against firearm owners, Florida’s law instructs that “[a] health care practitioner . . . may not intentionally enter any disclosed information concerning firearm ownership into the patient’s medical record” and “should refrain from making a written inquiry or asking questions concerning the ownership of a firearm or ammunition. . .”). A caveat exists where the practitioner believes in good faith that such information is “relevant to the patient’s medical care or safety, or the safety of others.” *Id.* at § 790.338(2).

27. Steven E. Weinberger et al., *Legislative Interference with the Patient-Physician Relationship*, 367 NEW ENG. J. MED. 1557, 1558–59 (2012), <http://www.nejm.org/doi/pdf/10.1056/NEJMsb1209858> [<http://perma.cc/8C84-NMR2>] (writing on behalf of the American Academy of Family Physicians, the American Academy of Pediatrics, the American College of Obstetricians and Gynecologists, the American College of Physicians, and the American College of Surgeons).

28. See James N. Kirkpatrick et al., *Bundling Informed Consent and Advance Care Planning in Chronic Cardiovascular Disease*, 175 JAMA INTERNAL MED. 5 (2015) (suggesting “bundling” informed-consent questions with advance care-planning conversations).

and so may not be truly holding to the best practices of their profession.<sup>29</sup>

When the end of the patient's life arrives, complications escalate for the practitioner and for the patient or his representative. The former must navigate medical and emotional concerns, and the latter have entered territory that is likely unfamiliar and unwanted. Even if the patient or physician has documented the patient's care preferences through advance-directive documents, which are generally legally binding, or "medical orders for life-sustaining treatment (MOLST)," which are medically binding,<sup>30</sup> the patient may not have designated a surrogate decision-maker to handle the crises for which is he unprepared. The federal Health Insurance Portability and Accountability Act of 1994 (HIPAA) authorized the Department of Health and Human Services to specify the type of information physicians can disclose to patients' surrogate decision-makers, as well as which categories of people may act as surrogates.<sup>31</sup> New York's Family Health Care Decisions Act elaborates on that requirement.<sup>32</sup>

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29. Thomas J. Smith & Dan L. Longo, *Talking with Patients about Dying*, 367 *NEW ENG. J. MED.* 1651 (2012).

30. See *NEW YORK STATE DEPT OF HEALTH, FREQUENTLY ASKED QUESTIONS* (Jan. 2012) [http://www.health.ny.gov/professionals/patients/patient\\_rights/molst/frequently\\_asked\\_questions.htm](http://www.health.ny.gov/professionals/patients/patient_rights/molst/frequently_asked_questions.htm) [<http://perma.cc/7MFH-VE96>] ("All health care professionals must follow these medical orders as the patient moves from one location to another, unless a physician examines the patient, reviews the order, and changes them."). See also *NEW YORK STATE DEPT OF HEALTH, MEDICAL ORDERS FOR LIFE-SUSTAINING TREATMENT*, [https://www.health.ny.gov/professionals/patients/patient\\_rights/molst](https://www.health.ny.gov/professionals/patients/patient_rights/molst) [<http://perma.cc/F6HM-QRAW>]. These documents may go by the name of "physician orders for life-sustaining treatments (POLST)," or similar variations, in other states. See generally A. Vandenbrucke et al., *POLST: Advance Care Planning for the Seriously Ill*, *POLST* (Sept. 26, 2013), <http://www.polst.org/wp-content/uploads/2015/01/2013.09.26-Final-POLST-Article.pdf> [<http://perma.cc/H7RZ-5RZC>]. The documents are not legally binding because they are solely medical, not legal, documents.

31. 42 U.S.C. § 1302(a) (1996) ("[T]he Secretary of Health and Human Services . . . shall make and publish such rules and regulations, not inconsistent with this chapter, as may be necessary to the efficient administration of the functions with which [the Secretary] is charged under this chapter."); 45 C.F.R. § 164.510(b)(1)(i) (2013) ("A covered entity may . . . disclose to a family member, other relative, or close personal friend of the individual . . . the protected health information directly relevant to such person's involvement . . .").

32. See *infra* Part III.A.

## B. WRITTEN DOCUMENTATION OF ADVANCE CARE-PLANNING

To maximize their utility, oral conversations and instructions are integrated into the patient's written medical record, in at least one of several ways. The most common way is through the attending physician's own brief notes about the patient's visit. Finding such notes when the patient needs urgent care, however, can be a daunting task. Another option is for the patient to fill out a document that is legally binding on the physician and surrogate decision makers, known as an "advance directive," that is, an *instruction* (directive) given by the patient *before* (in advance of) a time when it is needed.<sup>33</sup> A final option is a "medical order for life-sustaining treatment." Like any other medical order, these documents are instructions from the attending physician to the patient's current or future health care team.<sup>34</sup> This order is the medically binding counterpart to the legal advance directive. Furthermore, unlike legal advance directives, a "medical order for life-sustaining treatment" can be made binding outside of the hospital setting.<sup>35</sup> For example, the medical order may include a provision regarding "non-hospital Do Not Resuscitate" orders, which instructs paramedics not to administer CPR.<sup>36</sup>

There is truth to the stereotype among patients participating in advance care-planning that formalized requests are often aimed at reducing the amount of aggressive, curative treatments and increasing the amount of palliative care received.<sup>37</sup> That pattern indicates patients' general desire to counter some physicians' personal moralities and what is generally considered their profes-

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33. See, e.g., Sabatino, *supra* note 6 (quoting a 1997 Institute of Medicine report that discussed advance directives: "In this area of decision-making at the end of life, the law's favorite product — the legally binding document — may sometimes stand in the way of, rather than ease, the process . . .").

34. See NEW YORK STATE DEP'T. OF HEALTH, MEDICAL ORDERS FOR LIFE-SUSTAINING TREATMENT (2013), <https://www.health.ny.gov/forms/doh-5003.pdf> [<https://perma.cc/6MFN-H8XC>].

35. See NEW YORK STATE DEP'T. OF HEALTH, *supra* note 30.

36. *Id.*

37. Amber E. Barnato et al., *Are Regional Variations in End-of-Life Care Intensity Explained by Patient Preferences? A Study of the US Medicare Population*, 45 MED. CARE 5, 386, 390 (2007) ("Among a national sample of Medicare beneficiaries older than the age of 65, most prefer treatment focused on palliation rather than life-extension."). See also *supra* Part II (describing the form and uses of advance-care planning and advance directives).

sional obligation to employ aggressive diagnosis-based or curative treatment.<sup>38</sup>

The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), the largest investigation into end-of-life care, found that simply increasing advance care-planning and communication between physicians and patients had no significant effect on patients' quality of life.<sup>39</sup> Later studies demonstrated that when there is evidence of physicians actually following the written instructions, the action is correlated with higher quality of life at the end of the patient's life,<sup>40</sup> lower costs,<sup>41</sup> and less emotional burden on family members of the deceased.<sup>42</sup> Advance care-planning thus plays a significant role in promoting patient autonomy, as the conversations and resulting written notes or forms can inform physicians' and surrogates' health care decisions for the patient, when he cannot respond for himself.<sup>43</sup>

A prospective study assessing deaths between 1998 and 2007 found that even those patients with "treatment-limiting" advance directives generally received the same types of aggressive care as

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38. For a deeper discussion of the role of and interactions between physicians' morality and patients' wishes, see Atul Gawande, *Letting Go*, ANN. MED. (Aug. 2, 2010) (discussing the role of medicine and physicians when approaching a terminally ill patient's care).

39. The SUPPORT Principal Investigators, *A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)*, 274 JAMA 1591 (1995).

40. Alexi A. Wright et al., *Associations Between End-of-Life Discussions, Patient Mental Health, Medical Care Near Death, and Caregiver Bereavement Adjustment*, 300 JAMA 1665, 1668, 1671 (2008), [http://www.hvwa.org/images/jama\\_article\\_10\\_08.pdf](http://www.hvwa.org/images/jama_article_10_08.pdf) [<http://perma.cc/W8F9-9T5E>] (On a scale of 0 to 8, where 8 signified the highest "quality of life" rating, patients who participated in advance care-planning discussions and received less aggressive medical treatments had a mean score 6.4, while those who had no conversations and received three or more aggressive treatments had a mean score of 4.6, a statistically significant result.); Janice M. Leung et al., *The Effect of End-of-Life Discussions on Perceived Quality of Care and Health Status Among Patients with COPD*, 142 CHEST 128, 132 (2012) ("[P]atients who had had end-of-life discussions were more likely to rate their medical care as the best imaginable and to strongly agree that they were very satisfied with the medical care they received.").

41. Baohui Zhang et al., *Health Care Costs in the Last Week of Life: Associations with End-of-Life Conversations*, 169 ARCHIVES INTERNAL MED. 480, 484 (2009) ("Our findings demonstrate that advanced cancer patients who reported EOL conversations with physicians had lower medical costs in their final week of life compared to those who did not, which is largely a function of their more limited use of intensive interventions.").

42. Wright et al., *supra* note 24, at 1665, 1670 ("Our results suggest that end-of-life discussions may have cascading benefits for patients and their caregivers.").

43. Dan K. Morhaim & Keshia M. Pollack, *End-of-Life Care Issues: A Personal, Economic, Public Policy, and Public Health Crisis*, 103 AM. J. PUB. HEALTH e8, e9 (2013) ("Advance directives are critical to designating when, where, how, and how much care a person wants at the end of life.").

those without treatment-limiting directives.<sup>44</sup> Costs vastly differed, though, because the aggressive care for patients with advance directives was stopped sooner than for those without — not because curative treatment was avoided altogether.<sup>45</sup> Since all patients in such studies died as part of the study, there was no question about whether the aggressive treatment would save patients' lives; rather, the researchers' question was whether patients wanted to buy more time with an accompanying lower quality of life, or discontinue such treatments earlier but die more comfortably and peacefully.<sup>46</sup>

### III. EXAMINING NEW YORK STATE LAW AND ITS EFFECT ON PHYSICIAN PRACTICE

In addition to the Palliative Care Information Act (Information Act), the New York State Assembly has enacted two other laws, the Palliative Care Education and Training Act of 2007 (Education Act) and the Family Health Care Decisions Act of 2011 (Family Decisions Act), that affect a practitioner's ability to engage in productive advance care-planning with his patients or their caregivers.<sup>47</sup> These laws involve educating health practitioners about palliative care and establishing a prioritized list of "surrogate" decision-makers for when patients wait too long to lay out their end-of-life preferences. The Information Act falls somewhere between these two: under the Information Act, the practitioner is charged with educating his terminally ill patient about palliative care so that, if the patient cannot make or communicate his preferences as death nears, the physician need not rely wholly on the Family Decisions Act surrogate to ascertain the patient's wishes. A physician who neglects to conduct appropri-

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44. Lauren Hersh Nicholas et al., *Regional Variation in the Association Between Advance Directives and End-of-Life Medicare Expenditures*, 306 JAMA 1447, 1452 (2011) ("[W]hile treatment-limiting advance directives were associated with significantly lower total end-of-life Medicare expenditures in high-spending hospital referral regions, the relationship between treatment-limiting advance directives and the receipt of aggressive life-sustaining treatments . . . was less strong. This may suggest that treatment-limiting advance directives are associated with a quicker withdrawal . . .").

45. *Id.*

46. *Id.*

47. Palliative Care Education and Training Act, N.Y. PUB. HEALTH LAW § 2807-n (McKinney 2007); Family Health Care Decisions Act, N.Y. PUB. HEALTH LAW § 2994-d (McKinney 2011).

ate advance care-planning with a patient is considered to have committed a misdemeanor.<sup>48</sup>

A. RELEVANT NEW YORK LAW: THE PALLIATIVE CARE  
EDUCATION AND TRAINING ACT OF 2007 AND THE FAMILY  
HEALTH CARE DECISIONS ACT OF 2011

Before examining the Palliative Care Information Act, it is necessary to understand the two other New York laws that affect how end-of-life care is administered in the state. The 2007 Palliative Care Education and Training Act introduced grants for palliative-care curricula in undergraduate and graduate medical education programs.<sup>49</sup> This funding provision contains realistic goals and milestone marks, including the use of the well-established, seven-factor Palliative Education Assessment Tool to determine which palliative-care training programs merit funding, and ultimately designating such schools as Centers for Palliative Care Excellence.<sup>50</sup> The Education Act also provided for Palliative Care Practitioner Resource Centers to provide information to practitioners who might miss this medical-education opportunity.<sup>51</sup> Finally, the Education Act authorized the Commissioner of Health to establish a Palliative Care Education and Training Council, comprised of palliative-care experts, to provide technical information on the subject.<sup>52</sup>

Yet, eight years later, effects of this law are nowhere to be found. Searches on Google, Westlaw, SSRN, and PubMed provide no information on any particular school that has been named a Center for Palliative Care Excellence, nor on any empirical research into the success or failure of the Palliative Education As-

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48. See *infra* Part III.D.

49. Palliative Care Education and Training Act, §§ 2807-n(2)(d), 2807-n(3) (“The intent of this subdivision is to augment or increase palliative care . . . medical education.”).

50. *Id.* at §§ 2807-n(2)(c)(i), (3)(c)(i) (McKinney 2007) (“[P]lan to incorporate palliative care longitudinally throughout the medical school curriculum according to professionally recognized standards including, but not limited to, a plan that covers the seven domains identified in the Palliative Education Assessment Tool.”). Sharon Abele Meekin et al., *Development of a Palliative Education Assessment Tool for Medical Student Education*, 75 ACAD. MED. 986, 989 (2000). The tool lays out seven curricular domains necessary for a successful palliative-care program: palliative medicine, pain, neuropsychological symptoms, other symptoms, ethics and the law, patient/family/caregiver nonclinical perspectives on end-of-life care, and clinical communication skills.

51. Palliative Care Education and Training Act, § 2807-n(5).

52. *Id.* at § 2807-n(6) (“The New York State palliative care and training council is established in the department as an expert panel . . .”).

assessment Tool as a means of establishing palliative-care programs in New York.<sup>53</sup> Furthermore, a 2013 report to New York Governor Andrew Cuomo from the Spending and Government Efficiency Commission recommended replacing the Council, along with five other boards and committees, with “informal dialogue.”<sup>54</sup> However, as part of a 2014 amendment, the State Assembly voted to add home-care and social workers to the Training Council, ostensibly to make it stronger and more representative of relevant fields of care, as well as to include nursing and social work schools as eligible recipients for the Education and Training Act funding.<sup>55</sup>

New York’s 2011 Family Health Care Decisions Act (Family Decisions Act) instituted a default system of determining the identity of surrogate medical decision-makers for hospital and nursing-home patients, or any patients requiring decisions about hospice care, who lack the mental capacity to make such decisions for themselves.<sup>56</sup> This law serves as a safety net in situations in which patients are not able to, or choose not to, appoint

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53. Several articles have been written about implementing a palliative education assessment tool in German, Indian, and other international medical schools. See Christine Schiessl et al., *Undergraduate Curricula in Palliative Medicine: A Systematic Analysis Based on the Palliative Education Assessment Tool*, 16 J. PALL. MED. 20, 20 (2013) (“The aim of this study was to analyze international undergraduate curricula in palliative medicine, and thus support further curriculum development in Germany.”). See also Senthil P. Kumar et al., *Effects of Palliative Care Training Program on Knowledge, Attitudes, Beliefs and Experiences Among Student Physiotherapists: A Preliminary Quasi-experimental Study*, 17 INDIAN J. PALL. CARE 47 (2011) (analyzing the effect of Meekin’s Palliative Education Assessment Tool on a physical therapy institution in India). However, no analysis has been conducted in New York State since 2007. The only research in this area was conducted in 2002, though with promising conclusions, which may have resulted in the law’s passage. See Emily B. Wood et al., *Enhancing Palliative Care Education in Medical School Curricula: Implementation of the Palliative Education Assessment Tool*, 77 ACAD. MED. 285 (2002) (finding that in most of the participating medical schools, self-assessments regarding program implementation were generally positive; but that the program had not been in place long enough to produce any observable effect on the students’ practice of palliative medicine).

54. SPENDING AND GOV’T EFFICIENCY COMM’N, FINAL REPORT: FEB. 2013, 131 (2013) (listing the Palliative Care Education and Training Council among five boards and one committee that the Commission recommended eliminating).

55. Palliative Care Education and Training Act, § 2807-n(6) (McKinney 2014) (including in the list of Palliative Care Education and Training Council representatives “family physicians, nursing, social work, hospice, home care”).

56. Family Health Care Decisions Act, N.Y. PUB. HEALTH LAW § 2994-d (McKinney 2011). See also *id.* at § 2994-b (“This article shall apply to health care decisions regarding health care provided in a hospital, and to decisions regarding hospice care without regard to where the decision is made or where the care is provided . . .”).

surrogates before losing the mental capacity to do so.<sup>57</sup> When the patient is deemed to lack sufficient judgment,<sup>58</sup> the Family Decisions Act provides a standardized, prioritized list of individuals who may be able to elucidate the patient's wishes, beginning with the patient's guardian (if he has one), then the patient's spouse, and down to a "close friend," for six levels of priority in all.<sup>59</sup> A better-than-nothing law, the Family Decisions Act simplifies the attending physician's work and the treatment process as a whole because it gives legal authority to a single actor, or small group of actors, to make health care decisions on the patient's behalf.

Patients with Alzheimer's disease are examples of those who require the Family Decisions Act, because of the fluctuating nature of Alzheimer's disease symptoms. Upon admission to a hospital for a routine procedure, anesthesia or dehydration might affect the patient's cognition more than it would for a patient without underlying dementia. Statistically speaking, it is unlikely that an Alzheimer's patient will have designated a surrogate health care decision-maker,<sup>60</sup> so the Family Decisions Act would indicate to physicians which potential surrogate can speak on the patient's behalf.

Under the Family Decisions Act, the practitioner is legally required to listen to any and every surrogate at the applicable priority level. This is relatively straightforward when it comes to the spouse; however, if the patient has more than one family member of equal priority, such as two children, then under section 2994-d(1)(c), the practitioner may be required to wait for them to come to agreement.<sup>61</sup> The law calls on "one person from

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57. *Id.* § 2994-d(3)(ii) ("Nothing in this article shall obligate health care providers to seek the consent of a surrogate if an adult patient has already made a decision about the proposed health care. . . . If a surrogate has already been designated for the patient, the attending physician shall make reasonable efforts to notify the surrogate . . .").

58. *See* N.Y. PUB. HEALTH LAW § 2994-c (McKinney 2012) (detailing the methods for determining whether a patient retains the mental capacity for making decisions regarding medical care).

59. Family Health Care Decisions Act, N.Y. PUB. HEALTH LAW § 2994-d(1) (McKinney 2011). The list is, in order of priority: a guardian authorized to decide about health care; the spouse, if not legally separated from the patient, or the domestic partner; a son or daughter eighteen years of age or older; a parent; a brother or sister eighteen years of age or older; a close friend.

60. *See supra* Part II.

61. *See* Patricia L. Angley, *Resolving Conflicts Among Multiple Surrogates under the Family Health Care Decisions Act*, 25 ELDER & SPECIAL NEEDS L. J. 27, 29 (2015) ("[T]he FHCDA merely lists the hierarchy and priority of possible surrogates without specifying how, for example, two siblings with different views resolve conflicts about treatment decisions. . . . The law does not specify which adult child should become the surrogate.").



the following list from the class highest in priority . . .” but does not provide any guidance for selecting from between or among multiple individuals that fall within the same priority level.<sup>62</sup> For example, if a patient’s spouse is unavailable, due to distance, incapacity, or death, then the Family Decisions Act considers the opinions of three children to be of equal weight.<sup>63</sup> The law lists, in part, “the spouse,” “a son or daughter,” and “a parent;” the article “a” implies the law’s assumption that only one person should or will make the ultimate decision.<sup>64</sup> The law does not provide instruction for situations in which the co-surrogates cannot agree, which suggests that the physician must hope that all three children come to an agreement.<sup>65</sup> The physician is explicitly barred from “serv[ing] as surrogate,”<sup>66</sup> and opting for one individual over another to act as surrogate may illicitly implicate the physician in the patient’s treatment decisions. As a result, the physician must either wait for the individuals within the priority-class to decide on a spokesperson, or else treat all three of the patient’s children as a single, aggregate, surrogate decision-maker. The Family Decisions Act only brings in the relevant institution’s ethics committee or “a court of competent jurisdiction” for decisions regarding refusal of life-sustaining treatments,<sup>67</sup> and defers to an attending physician’s medical judgment only in cases in which a surrogate decision-maker cannot be located.<sup>68</sup> However, the law does nothing to address the underlying problem of not knowing what the patient would have wanted for himself.

The Family Decisions Act also provides for cases in which the patient wavers between gaining and losing the ability to make medical decisions as his symptoms ebb and flow. Section 2994-d(3)(b) states, “In the event an attending physician determines that the patient has regained decision-making capacity, the au-

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62. N.Y. PUB. HEALTH LAW § 2994-d(1) (2012).

63. N.Y. PUB. HEALTH LAW § 2994-d(1)(c) (2012). See Angley, *supra* note 61, at 29.

64. N.Y. PUB. HEALTH LAW § 2994-d(1)(b)–(d) (2012).

65. *Id.*

66. N.Y. PUB. HEALTH LAW § 2994-d(2) (McKinney 2011) (“If a physician serves as surrogate, the physician shall not act as the patient’s attending physician after his or her authority as surrogate begins.”).

67. *Id.* §§ 2994-d(5)(b)–(c) (“[A] surrogate shall have the authority to refuse life-sustaining treatment . . . only if the ethics review committee, . . . or a court of competent jurisdiction, reviews the decision.”).

68. *Id.* §§ 2994-g(4)(b)(i), (iii) (“An attending physician shall make a recommendation in consultation with hospital staff . . .”).

thority of the surrogate shall cease.”<sup>69</sup> Such a provision is important for those in similar situations to those of Alzheimer’s patients, who may have “good days” and “bad days” which cannot be predicted well in advance.

Finally, the law contains a “conscientious objection” provision, which allows hospitals to refuse to abide by a patient’s health care decisions, if they contravene the private hospital’s “formally adopted policy,” and gives similar authority to individual practitioners if the patient’s requests are “contrary to the individual [practitioner]’s sincerely held religious beliefs or sincerely held moral convictions.”<sup>70</sup> Because of this provision, regardless of who is on the receiving end of the advance care-planning conversations, the practitioner may not be obligated to follow any of their instructions.

The lack of both conspicuous implementation and empirical analysis of the Education and Training Act is most noticeably a problem because of the New York State Assembly’s later passage of the Information Act.<sup>71</sup> The Information Act requires practitioners to hold advance care-planning conversations, but it includes no educational component for the practitioners themselves.<sup>72</sup> It accordingly relies, implicitly but heavily, on the earlier Education Act to ensure that practitioners are adequately prepared to comply with the Information Act’s conversational mandate.

## B. IDENTIFYING NECESSARY PARTIES TO PALLIATIVE CARE INFORMATION ACT CONVERSATIONS

The Information Act offers detailed definitions and instructions for determining which categories of practitioners and patients it governs. The Information Act begins with a definitions section, which delineates which practitioners fall into the category of “attending health care practitioner” and which patients are

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69. *Id.* §§ 2994-d(5)(b)–(c).

70. *Id.* §§ 2994-n(1)(a), (2)(a) (describing exemptions for hospitals and individual practitioners to avoid following a patient’s medical directives).

71. Palliative Care Patient Information Act, N.Y. PUB. HEALTH LAW § 2997-c (McKinney 2013) (hereinafter “Information Act”) (requiring physicians to teach terminal patients about palliative care, regardless of the physician’s expertise and training).

72. *Id.* § 2997-c(2)(a) (“If a patient is diagnosed with a terminal illness or condition, the patient’s attending health care practitioner shall offer to provide the patient with: (a) information and counseling regarding palliative care and end-of-life options appropriate to the patient . . .”).

deemed to have a “terminal illness or condition” so as to be governed by the statute.”<sup>73</sup> Section 2997-c(1)(b) clarifies that not every practitioner licensed in New York State is governed by this law. Rather, only the “physician or nurse practitioner . . . who has primary responsibility for the care and treatment of the patient” is governed by this statute.<sup>74</sup> Where more than one practitioner share the “primary responsibility,” the statute applies to them equally,<sup>75</sup> unless the multiple practitioners “agree to assign that responsibility” to just one between or among them.<sup>76</sup> Even in cases in which a nurse practitioner is ostensibly “primarily” responsible for the conversation, the overseeing physician may be held accountable, as well. Section 2997-c(1)(b) also applies not only to physicians but also to nurse practitioners.<sup>77</sup> This means that if a physician oversees, but is not directly involved in, a nurse practitioner’s care of a patient, the role of “primarily” responsible practitioner could be shared between the two.

A recent piece in the *New England Journal of Medicine* highlighted the difficulty in determining who, exactly, is primarily responsible for a patient’s care.<sup>78</sup> The three authors present strong cases for this responsibility lying with, respectively, the primary care physician, as he is the general overseer of a patient’s care;<sup>79</sup> the patient’s team of experts, since they have the greatest familiarity with the patient’s particular prognosis;<sup>80</sup> or a palliative-care physician brought on for this specific reason, since she has the most comprehensive understanding of patients’ needs after receiving terminal diagnoses.<sup>81</sup> The arguments in favor of

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73. *Id.* §§ 2997-c(1)(b), (d).

74. *Id.* § 2997-c(1)(b).

75. *Id.*

76. *Id.*

77. *Id.* (“Attending health care practitioner’ means a physician or nurse practitioner . . .”).

78. *End-of-Life Advance Directive*, 372 *NEW ENG. J. MED.* 667 (2015), <http://www.nejm.org/doi/full/10.1056/NEJMc1411152> [<http://perma.cc/62MJ-95L3>] (highlighting the difficulty inherent in the practical decision of whether a “primary care” physician is really the “primary” caregiver for a patient, particularly if he has much less familiarity with the patient and his case than the patient’s team of experts).

79. *Id.* at 668 (“A relationship with continuity is the ideal context for a stepwise approach to discussing the goals of care.”).

80. *Id.* (“The oncology team should take responsibility for initiating conversations about goals of care . . . because of their current knowledge of [the patient’s] clinical status, their subspecialty-level knowledge of the disease trajectory, the trust they have built with [the patient], and their moral duty not to abandon the patient at the end of life.”).

81. *Id.* at 669 (“[The patient] needs more — not less — intensive medical and social support at this stage in her life.”).

each type of caregiver reveal the faults with the others: Meier points out that “most primary care clinicians and specialists don’t have time to manage complex symptoms, as well as emotional, practical, spiritual, and family needs . . . .”<sup>82</sup>

These specifications notwithstanding, sections 2997-c(2)(b) and 2997-c(3) affirm that the primarily responsible practitioner may transfer this counseling task to another “professionally qualified individual” if the primary practitioner “is not willing or does not feel qualified” to act under this section.<sup>83</sup>

When the Information Act was enacted in 2010, section 2997-c(3) only stated, “Where the attending health care practitioner is *not willing* . . . .”<sup>84</sup> The State Assembly added the phrase, “or does not feel qualified,” in 2013.<sup>85</sup> This amendment is significant, in part, because a willful violation of a New York health law, such as this one, can lead to imprisonment of up to one year or a fine of up to \$10,000.<sup>86</sup> Under the original Information Act, “feeling unqualified” was not explicitly a valid reason to defer to another physician. The 2013 amendment encourages ill-prepared physicians to pass the responsibility to another practitioner and avoid these punishments altogether. The state legislature does not address why the Information Act includes two similar, but differently worded, exemptions. It is possible that the exemption embedded in section 2997-c(2)(b) is specific to the fact of providing information and counseling, while the exemption in section 2997-c(3) pertains more generally to the idea of counseling a patient on end-of-life care as an option, even where other options include curative- or symptom-based treatments. However, even this amendment does not address the outcome, legal or otherwise, of a situation in which the practitioner cannot find another to take his place.

The Information Act contains no suggestions or requirements for disseminating educational information to practitioners, espe-

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82. *Id.* (highlighting why a patient should be referred to a palliative care physician to tackle end-of-life needs, rather than relying on a primary-care physician or a team of experts).

83. N.Y. PUB. HEALTH LAW § 2997-c(3) (McKinney 2013).

84. N.Y. PUB. HEALTH LAW § 2997-c(3) (McKinney 2010) (eff. until Jan. 14, 2013).

85. N.Y. PUB. HEALTH LAW § 2997-c(3) (McKinney 2013) (adding the clause “or does not feel qualified” to the 2010 version to clarify that while a physician may be willing to hold a conversation, feeling unqualified to do so eclipses the importance of that willingness).

86. N.Y. PUB. HEALTH LAW § 12-b(2) (McKinney 2014). Effective Apr. 1, 2017, the financial penalty will be reduced to \$2000 from \$10,000. *Id.*

cially those outside of the palliative-care specialty, who presumably need the most support and, according to some scholars and practitioners, should be “primarily responsible” for the patient.<sup>87</sup> Perhaps this oversight was a result of the 2007 Education and Training Act; but the Education and Training Act has gained little-to-no visible traction.<sup>88</sup> Thus, within a year of the Information Act’s original enactment, it had already come under fire from individual physicians<sup>89</sup> as well as the New York Chapter of the American College of Physicians.<sup>90</sup> Their concerns stemmed from the New York State Assembly’s poor communication and lack of consultation with physician groups when generating this legislation, as well as the overall vagueness of the statute.<sup>91</sup>

As such, the main controversy surrounding the definitions listed in the Information Act was not about which practitioners were required to act, but rather about which patients fell within the meaning of having a “terminal illness or condition.”<sup>92</sup> Section 2997-c(1)(d) defines a “terminal illness or condition” as one “which can reasonably be expected to cause death within six months, whether or not treatment is provided.”<sup>93</sup> Physicians and

87. *End-of-Life Advance Directive*, *supra* note 78 (explaining why primary-care physicians and specialists, respectively, should review the patient’s advance care-planning needs, rather than a palliative-care physician); Anthony L. Back, *Treatment Option 2: Recommend that the Oncology Team Discuss the Goals of Care with the Patient*, 372 *NEW ENG. J. MED.* 668 (2015), <http://www.nejm.org/doi/full/10.1056/NEJMcld1411152#t=cldeOpt2> [<http://perma.cc/S7H9-J6PT>].

88. *See supra* Part III.A.

89. Alan B. Astrow & Beth Popp, *The Palliative Care Information Act in Real Life*, 364 *NEW ENG. J. MED.* 1885 (2011), <http://www.nejm.org/doi/full/10.1056/NEJMp1102392> [<http://perma.cc/P9Q3-4ZVH>] (“[P]hysicians need to feel comfortable communicating their own values and experiences and providing nonauthoritarian guidance and support while expressing interest in and respect for the experience and values of patients and families.”).

90. Letter from Mary Rappazzo, Past-President, N.Y. Chapter of the Am. Coll. of Physicians, to Jeffrey M. Drazen, Editor, *The New England Journal of Medicine* (June 3, 2011) (on file with author) (“To be clear, while we support open, honest communication with patients and their families and provide compassionate care in difficult times, the New York Chapter of ACP opposed the Palliative Care Information Act because of the very nature of its intrusion and its mandate.”).

91. *See Astrow & Popp, supra* note 89 (noting that the law “was passed with little public discussion and without adequate consultation with the primary groups that will have to implement it. . . . One problem is the vagueness of the category of ‘terminal illness’ on which the law focuses.”).

92. Memorandum from the Div. of the Budget to the N.Y. State Assembly 12 (Aug. 12, 2010) (on file with author); Memorandum from the State of N.Y. Dep’t of Health to the N.Y. State Assembly 18 (Aug. 10, 2010) (on file with author). Both memoranda point out that the definition of “terminally ill” is too broad because people with diabetes are not necessarily at the end of their lives. *See also* Astrow & Popp, *supra* note 89 (discussing the problem of the vagueness of the “terminal illness” focus of the law).

93. N.Y. PUB. HEALTH LAW § 2997-c(1)(d) (McKinney 2013).

others maintain that this definition is not as straightforward as it might seem.<sup>94</sup> According to one study, seventy-five percent of people in the United States “die of conditions other than cancer, such as cardiovascular disease, chronic lung disease, Alzheimer’s disease, and other illnesses whose timing and course are far less predictable.”<sup>95</sup> More specifically, the New York Division of the Budget and the New York State Department of Health pointed out that technically, diabetes fell within section 2997-c(1)(d)’s definition because although diabetes is easily treatable and generally considered a chronic, rather than life-threatening, disease, it can be fatal in as little as six months if left untreated.<sup>96</sup> The concern is that an individual diagnosed with a common chronic condition may be counseled about his end-of-life options in a way that implies that non-curative treatments are the only options available.

However, the law does not bar the attending practitioner from counseling a patient about curative treatments;<sup>97</sup> the Information Act’s purpose is to ensure that all patients with “terminal” conditions give truly informed consent, which requires understanding *all* viable options. This means alerting a patient to his right to information regarding curative, palliative, end-of-life, and other, such as non-biomedical, options. In 2013, the Assembly amended the Information Act to include other options more pointedly. Specifically, the law now requires informing patients of both “palliative care and end-of-life options” and “other appropriate treatment options should the patient wish to initiate or continue treatment.”<sup>98</sup> This amendment ensures that diabetic and other similarly situated patients will learn not only about the palliative options available for their end-stage renal disease, but also about

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94. See *supra* note 90, at 669.

95. Astrow & Popp, *supra* note 89 (pointing out that prognostication is more difficult for some diseases than others).

96. Information Act, *supra* note 71; Memorandum from the Div. of the Budget to the N.Y. State Assembly 12, *supra* note 92 (“This definition is problematic as certain conditions, such as diabetes, are likely to cause death within a short period of time if not treated.”); Memorandum from the State of N.Y. Dep’t of Health to the N.Y. State Assembly 18, *supra* note 92 (“[T]he bill language is overbroad. . . . Certain conditions, such as diabetes, are likely to cause death within a short period of time if not treated.”).

97. See *infra* Part III.B.

98. Information Act, N.Y. PUB. HEALTH LAW § 2997-c(2) (McKinney 2013) (the previous version did not include the clause “information regarding other appropriate treatment options should the patient wish to initiate or continue treatment”; this was added as section 2(b) in the 2013 version.).

the way dialysis works, the risks and benefits of transplant, and perhaps even Medicare's coverage of related treatment.

The Information Act also provides for situations in which the patient lacks the mental capacity to make health care decisions for himself. In such a case, the practitioner "shall provide information and counseling under this section to a person with authority to make health care decisions for the patient."<sup>99</sup> If the patient has already engaged in advance care-planning, then he may have already assigned a surrogate decision-maker through the appropriate legal forms. If not, the physician must know where else to search for a surrogate, since section 2997-c does not provide guidance for determining who might have such "authority."

The relationship between the Family Decisions Act and the Information Act is not always clear. The Family Decisions Act only applies to decisions about health care that are provided in hospitals, unless the surrogate is required to make a decision regarding hospice care, in which case the decision can be made anywhere and about any type of hospice-related care.<sup>100</sup> Because the Information Act purports to be about palliative and end-of-life care, including hospice, a surrogate appointed under the Family Decisions Act might be considered to have the "authority to make health care decisions for the patient."<sup>101</sup> However, a surrogate who would opt for curative treatment on the patient's behalf may actually be barred from doing so, unless his lawyer can argue that a decision not to consider hospice care should be considered a decision "regarding" hospice care.<sup>102</sup>

Lastly, section 2997-c(2) uses a passive voice to describe the information-recipient's identity: "If a patient *is diagnosed* with a

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99. *Id.* § 2997-(b).

100. N.Y. PUB. HEALTH LAW § 2994-b (McKinney 2011) ("This article shall apply to health care decisions regarding health care provided in a hospital, and to decisions regarding hospice care without regard to where the decision is made or where the care is provided.")

101. Information Act, § 2997-c(2)(b) ("Where the patient lacks capacity to reasonably understand and make informed choices relating to palliative care, the attending health care practitioner shall provide information and counseling under this section to a person with authority to make health care decisions for the patient.")

102. The exact language of N.Y. PUB. HEALTH LAW § 2997-a(5a) (McKinney 2011) states that "decisions regarding hospice care" means "the decision to enroll or disenroll in hospice. . . ." It is not clear from the text whether a decision to avoid enrolling in hospice altogether would fall within that language.

terminal illness . . . .”<sup>103</sup> The use of the passive voice avoids drawing any relationship between the practitioner who delivers the diagnosis and the one responsible for communicating the patient’s rights and information to him. Instead, it places a greater burden on physicians to have an internal debate matching the written one by Tolle, Back, and Meier.<sup>104</sup> The statute thus provides some leeway over which practitioner must hold these conversations. On the other hand, it creates an unnecessary additional step for practitioners who, in addition to tending to their patients’ needs, must now determine whether the patient has received diagnostic or other information from other practitioners — and whether such information was accurate and appropriate for that patient’s ever-changing health status.

### C. INFORMATION REQUIRED UNDER THE PALLIATIVE CARE INFORMATION ACT

In addition to detailing which practitioners and patients it regulates, the Information Act spells out what conversation topics the practitioner must address. The definitions section of section 2997-c(1) also clarifies the meaning of “palliative care” as it is used in the rest of the subsection.<sup>105</sup> The Information Act’s definition of “palliative care” is not exclusively about end-of-life care, as it encompasses times when palliative care may be applicable outside the end-of-life context. However, the Act’s definition does highlight end-of-life options and does not explicitly address the possibility of administering palliative care alongside curative treatments.

Subsection (2) of the Information Act contains the bulk of what the practitioner must provide for his patient. There are two

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103. Compare *id.* § 2997-c(2) with CAL. HEALTH & SAFETY CODE § 442.5(a) (West 2015) (providing specific instructions on identifying the practitioners governed under the statute). See *supra* Part III.A.

104. *End-of-Life Advance Directive*, *supra* note 78; Anthony L. Back, *supra* note 87; Diane E. Meier, *Option 3: Refer the Patient to a Palliative Care Physician Who Will Discuss the Goals of Care with the Patient*, 372 NEW ENG. J. MED 669 (2015), <http://www.nejm.org/doi/full/10.1056/NEJMclde1411152#t=cldeOpt3> [<http://perma.cc/W62H-EVMS>]. Tolle, Back, and Meier advocate for primary-care physicians, specialists, or palliative-care physicians, respectively, to have the duty of reviewing the patient’s advance care-planning needs.

105. The definition of “palliative care” enlisted in the Information Act differs from the one in this Note, *supra* note 1, only in that § 2997-c(1) leaves out “psychosocial and spiritual support” from the list of covered topics.



main clauses, the first included in 2010 and the latter added in 2013. The first clause, making up section 2997-c(2)(a), requires the physician to provide “information and counseling regarding palliative and end-of-life options appropriate to the patient.”<sup>106</sup> This phrasing hews closely to the definition of palliative care provided in section 2997-c(1)(c). In the original 2010 enactment, section 2997-c(2) contained only this requirement for palliative and end-of-life options. For an elderly, diabetic patient with end-stage renal disease, that meant that a practitioner striving to follow the letter of the statute would provide guidance for his patient about the care options that would ease his pain, and perhaps even provide information about hospice care. For a middle-aged patient, it is hard to believe that any practitioner would take any diagnosis as unequivocally fatal. Regardless of the exact wording of the statute, the practitioner’s professional standards and training would guide him toward “appropriate” counseling for each patient.<sup>107</sup>

The 2013 amendment to the Information Act requires two topics of conversation from the attending practitioner. In the original 2010 law, as well as the amended version, the practitioner was required to counsel his patient “regarding palliative *and* end-of-life options.”<sup>108</sup> As cited above, physicians and state government departments raised concerns over the vagueness of “terminal illness,” and their fears that individuals with treatable conditions, like diabetes, would be obliged to listen to information on end-of-life care, rather than on how to manage and treat basic symptoms.<sup>109</sup> The 2013 amendment addressed this concern, clarifying that the counseling should include “other appropriate

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106. Information Act, § 2997-c(2)(a) (specifying that the practitioner must provide the patient with end-of-life, not only curative, options).

107. *Id.* § 2997-c(1)(a) (This section defines “appropriate” options for each patient as those “consistent with applicable legal, health and professional standards; the patient’s clinical and other circumstances; and the patient’s reasonably known wishes and beliefs.”).

108. *Compare* N.Y. PUB. HEALTH LAW § 2997-c(2) (eff. until Jan. 14, 2013) (“[T]he patient’s attending health care practitioner shall offer to provide the patient with information and counseling regarding palliative care and end-of-life options . . .”) *with* N.Y. PUB. HEALTH LAW § 2997-c(2)(a) (eff. Jan. 14, 2013) (“information and counseling regarding palliative care and end-of-life options . . .”).

109. Memorandum from the Div. of the Budget to the N.Y. State Assembly 12, *supra* note 92; Memorandum from the State of N.Y. Dep’t of Health to the N.Y. State Assembly 18, *supra* note 92. Both memoranda point out that the definition of “terminally ill” is too broad because people with diabetes are not necessarily at the end of their lives. *See also* Astrow & Popp, *supra* note 89 (discussing the problem of the vagueness of the “terminal illness” focus of the law).

treatment options, should the patient wish to initiate or continue treatment.”<sup>110</sup> The wording of this section implies that the practitioner must counsel on such curative treatments only if the patient first states that he would like to “initiate or continue” non-palliative options. Given that only a minority of patients even reach the point of planning for end-of-life care, it appears that most practitioner-patient consultations focus on curative, not end-of-life, care, so the late addition of section 2997-c(3) was likely a formality.<sup>111</sup>

#### D. ENFORCEMENT ACTION AGAINST PHYSICIAN NON-COMPLIANCE WITH THE PALLIATIVE CARE INFORMATION ACT

New York State enforces the Information Act in the same way as it enforces the rest of the Public Health Law.<sup>112</sup> Violation of the Information Act’s mandate to hold advance care-planning conversations is considered a misdemeanor.<sup>113</sup> However, the Information Act is not likely to be enforced criminally, but rather administratively.<sup>114</sup> Slightly complicating matters, the bodies responsible for administratively enforcing the law and disciplining practitioners differ based on whether a physician or a nurse practitioner is suspected of violating the law’s mandate.

New York’s Public Health Law can be enforced through section 12-b of the Law. Under this section, a willful violation of any provision of the state’s health law can lead to a fine of up to

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110. Information Act, § 2997-c(2)(b) (this subsection added a requirement that physicians discuss symptom-management or curative treatments if the terminally ill patient chooses those paths instead of palliative or end-of-life choices).

111. DEPT HEALTH AND HUMAN SERV., *supra* note 20. *See generally supra* Part I.A (providing additional research and context to support the assertion that just a small percentage of patients engage in advance care-planning).

112. There is no case law that cites to § 2997-c.

113. N.Y. PENAL LAW § 55.10(2)(c) (McKinney 1978) (“[W]here an offense is defined outside this chapter and a sentence to a term of imprisonment in excess of fifteen days but not in excess of one year is provided in the law or ordinance defining it, such offense shall be deemed an unclassified misdemeanor.”).

114. *See* N.Y. STATE UNIFIED COURT SYS. & N.Y. STATE BAR ASS’N, NEW YORK PUBLIC HEALTH LEGAL MANUAL 17–18 (N.Y. State Bar Ass’n, ed., 2011), <https://www.nycourts.gov/whatsnew/pdf/PublicHealthLegalManual.pdf> [<https://perma.cc/32PP-HKHQ>] (commenting that the remedy of “criminal arrest and prosecution” may be necessary only in cases posing “immediate danger” to the community).

\$10,000 or a term of imprisonment up to one year,<sup>115</sup> which is considered an unclassified misdemeanor.<sup>116</sup>

The Office of Professional Medical Conduct oversees disciplinary actions against physicians, while the State Education Department, through its Office of the Professions and Office of Professional Discipline, and guided by the Board of Regents, governs the discipline of nurse practitioners.<sup>117</sup>

New York State's Office of Professional Medical Conduct is authorized under section 230 of the Public Health Law to oversee matters of physician "professional misconduct," as defined in section 6530 of the state's Education Law.<sup>118</sup> Section 6530(16) lists the definition of "professional misconduct" relevant to practitioners' failure to comply with the Information Act's mandate: "A willful or grossly negligent failure to comply with substantial provisions of federal, state, or local laws, rules, or regulations governing the practice of medicine."<sup>119</sup> Section 230(7)(a) clarifies that the subsection covers only physicians, excluding nurse practitioners.<sup>120</sup> Misconduct by nurse practitioners is defined under an almost identical provision in section 29.1 of Title 8 of the New York Code of Rules and Regulations, housed within the Rules of the Board of Regents.<sup>121</sup>

Under section 230-a of the Public Health Law, the Office of Professional Medical Conduct can assess penalties against physicians who engage in misconduct, including a fine of up to

115. N.Y. PUB. HEALTH LAW § 12-b(2) (McKinney 2014) ("A person who willfully violates any provision of this chapter . . . is punishable by imprisonment not exceeding one year, or by a fine not exceeding ten thousand dollars or by both.").

116. N.Y. PENAL LAW, *supra* note 113.

117. *Compare* N.Y. PUB. HEALTH LAW § 230(1) (McKinney 2015) ("A state board for professional medical conduct is hereby created in the department in matters of professional misconduct as defined in section [ ] sixty-five hundred thirty . . . of the education law.") with N.Y. COMP. CODES R. & REGS. tit. 8, § 29.1 (1996). *See also* *The Licensed Professions in New York State*, OFFICE OF THE PROFESSIONS (Feb. 26, 2015), <http://www.op.nysed.gov/> [<http://perma.cc/84QP-2Y67>].

118. N.Y. PUB. HEALTH LAW, *supra* note 117.

119. N.Y. EDUC. LAW § 6530(16) (McKinney 2008) (this section does not explicitly address the Information Act).

120. N.Y. PUB. HEALTH LAW, *supra* note 117, § 230(7)(a) (defining "licensee" as a "physician, including a physician practicing under a limited permit, a medical resident, physician's assistant and specialist's assistant," a list which excludes nurse practitioners).

121. N.Y. COMP. CODES R. & REGS., *supra* note 117 ("Unprofessional conduct in the practice of any profession licensed . . . shall include: (1) willful or grossly negligent failure to comply with substantial provisions of Federal, State or local laws, rules or regulations governing the practice of the profession . . .").

\$10,000.<sup>122</sup> The Office can also censure and reprimand; suspend, limit, or revoke the license; or require that the physician attend a training course, among other options.<sup>123</sup> The Board of Regents, similarly, has the power to assess fines and administratively prosecute nurse practitioners.<sup>124</sup> Generally speaking, the state initially moves for civil enforcement through fines and other remedies, and only criminally prosecutes physicians who pose immediate danger.<sup>125</sup> Such a harsh punishment is unlikely in the case of simply failing to hold a conversation.

#### IV. EXAMINING PATIENT “RIGHT TO INFORMATION” LAWS IN OTHER STATES

In 1996, Michigan became the first state to enact legislation affirming a patient’s right to information regarding palliative and end-of-life care, known as the Michigan Dignified Death Act.<sup>126</sup> Section 333.5653 outlines the identities of the governed parties, and section 333.5654 describes required oral communication, while section 333.5655 requires the physician to provide additional information both orally and in writing. Section 333.5657 immunizes the physician from liability in certain circumstances.<sup>127</sup>

Thirteen years later, Vermont enacted its Patient’s Bill of Rights for Palliative Care and Pain Management.<sup>128</sup> Only section 1871(b) of this law corresponds to New York’s Information Act; it states simply that “a patient with a terminal illness has the right to be informed by a clinician of all available options related to terminal care,” and to request or reject any such options.<sup>129</sup>

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122. N.Y. PUB. HEALTH LAW § 230-a(7) (McKinney 2008) (“The penalties which may be imposed by the state board for professional medical conduct . . . are: (7) A fine not to exceed ten thousand dollars . . .”).

123. *Id.* §§ 230-a(1)–(4), 230-a(8).

124. *See Enforcement Actions*, OFFICE OF THE PROFESSIONS (Mar. 10, 2015), <http://www.op.nysed.gov/opd/raresearch.htm> [<http://perma.cc/45BP-M5KQ>].

125. *Supra* note 114.

126. MICH. COMP. LAWS ANN. §§ 333.5651–333.5661 (West 2005). This should not be confused with other states’ “death with dignity” acts, which generally refer to physician-aided death; this law is solely an informed-consent law.

127. *See id.* § 333.5657.

128. Patient’s Bill of Rights for Palliative Care and Pain Management, ch. 42A, 2009 Stat. 159, 160 (2009) (codified at VT. STAT. ANN. tit. 18 § 1871(b)).

129. *Id.* Only one line of the law is related to terminal patients’ rights; the rest of the section is about patients’ rights more generally.

Finally, effective in 2015, California's Health and Safety Code section 442.5 has a similar right-to-know law.<sup>130</sup> This law strikes a balance between the conversations that are required between patients and physicians, and that which are based only upon the patient's initial request.

Michigan, with its multipart statute detailing everything from patient advocacy<sup>131</sup> to practitioner legal immunity,<sup>132</sup> falls at one end of a spectrum, while Vermont's one-line directive lies at the other end. California, like New York, falls somewhere in the middle, as it actively acknowledges the uniqueness of each patient's circumstances but still applies a single broad mandate to them all.<sup>133</sup>

#### A. IDENTIFYING NECESSARY PARTIES FOR DISCUSSING A TERMINALLY ILL PATIENT'S CARE IN MICHIGAN, VERMONT, AND CALIFORNIA

The laws of Michigan, Vermont, and California suggest or define which practitioners can or must initiate these advance care-planning discussions and what category of patient or surrogate must be involved.

Michigan's law is restricted in applicability to "a physician who has diagnosed a patient as having a reduced life expectancy due to advanced illness" and "is recommending medical treatment."<sup>134</sup> This means that only the physician who delivers the initial diagnosis is governed by Michigan's statute.<sup>135</sup> The second half of this subsection does not exactly narrow the statute's applicability, as all physicians, in delivering diagnoses, will recommend some sort of medical treatment. However, the current attending physician may not always be the one who diagnosed the

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130. CAL. HEALTH & SAFETY CODE §§ 442, 442.5, 442.7 (West 2015) ("[T]he health care provider shall . . . notify the patient of his or her right . . . to comprehensive information and counseling regarding legal end-of-life options.").

131. MICH. COMP. LAWS ANN., *supra* note 126, § 333.5653(1)(f) (citing the definition of "patient advocate" as set out in MICH. COMP. LAWS ANN. § 700.5509(1) (West 2005) (giving the same duties and authority to a patient advocate as a typical surrogate decision-maker might have)).

132. MICH. COMP. LAWS ANN., *supra* note 126, § 333.5657.

133. CAL. HEALTH & SAFETY CODE, *supra* note 130, § 442.5. For example, the law refers to "cultural sensitiv[ity]" and the possibility that someone other than the diagnosing physician may be a more appropriate participant in these conversations. *Id.*

134. MICH. COMP. LAWS ANN., *supra* note 126, § 333.5654(1).

135. This appears to render the second half of section 333.5654(1) superfluous.

patient. For example, a cancer patient may have received a diagnosis from one oncologist, who then transferred the patient to a different facility for primary treatment. Because modern health care relies on specialists for diagnoses, primary-care physicians in Michigan are generally not held responsible for counseling patients under this statute.

The benefit of New York's Information Act over Michigan's law is that the passive voice used in New York — "if a patient is diagnosed"<sup>136</sup> — suggests that the Information Act applies to any physician whose patient has received a terminal diagnosis, not only those who actually made the diagnosis. This broader application, in turn, means that the population's general understanding of palliative care could potentially grow in a swifter, yet more naturally conversational, way.

In 2000, Michigan's law defined "terminal illness" as a disease that the physician anticipated would lead to a patient's death within 6 months.<sup>137</sup> One year later, the state Legislature replaced "terminal illness" with "advanced illness" and provided a much more nuanced definition: it "means a medical or surgical condition with significant functional impairment that is not reversible by curative therapies and that is anticipated to progress toward death despite attempts at curative therapies or modulation, the time course of which may or may not be determinable through reasonable medical prognostication."<sup>138</sup> The Michigan legislature was seemingly responding to physicians, like those upset with the Information Act's vague six-month time limit, because the law's new wording clearly takes care to avoid mention of a particular length of prognosis. It also narrows the definition from "disease" to a specifically "medical or surgical" condition, and importantly, clarifies that curative therapies must not stop the progress toward death.<sup>139</sup>

This was the concern with diabetic patients in New York: while untreated diabetes could be fatal in six months, curative therapies, like a kidney transplant, could provide a decades-longer prognosis. Though New York's law does say "six months,

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136. Information Act, N.Y. PUB. HEALTH LAW § 2997-c(2) (McKinney 2013).

137. MICH. COMP. LAWS ANN. § 333.5653(1)(h) (West 2000) (amended 2002) ("Terminal illness' means a disease or condition due to which, in the opinion of a physician, a patient's death is anticipated within 6 months after the date of the physician's opinion.").

138. MICH. COMP. LAWS ANN., *supra* note 126, § 333.5653(1)(a).

139. *Id.*

whether or not treatment is provided,” which seems to mean the same thing as Michigan’s law, the latter is much more explicit with the idea that curative treatment will have little to no bearing on the condition’s progression. Then again, the lack of timeline would be frustrating to those who acknowledge that everyone is constantly progressing toward death, so that the question of “when” is paramount.

Vermont, for its part, defines “clinician” in another section of the chapter, as a medical doctor, an osteopathic physician, an advance practice registered nurse, and a physician’s assistant.<sup>140</sup> However, section 1871(b) does not discuss the need for any prior relationship between the clinician and the patient requiring information.<sup>141</sup> If a frail, elderly diabetes patient were to go to a dialysis center and express a sentiment of suffering and distress resulting from the therapy, any “clinician” at the center might fall under the governance of section 1871, and would therefore be compelled to educate this patient about his rights to palliative and end-of-life care, in addition to or in place of dialysis. Vermont’s law goes even farther than New York’s broad definition of “attending health care practitioner.”<sup>142</sup> It seems to encompass more than just the “attending” clinician, instead reaching any clinician who might encounter the patient. This places a mandate on clinicians who are not familiar with the patient’s personal beliefs and medical history in the way that the patient could communicate only within a long-standing or trusting clinician-patient relationship. However, the fact that New York uses the word “attending” does not suddenly ensure that this physician is familiar with, for example, the patient’s moral and spiritual values. As pointed out by Back in the *New England Journal of Medicine*, a patient’s primary-care physician is not necessarily the practitioner who is most familiar with the patient’s background, prognosis, and plans.<sup>143</sup>

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140. VT. STAT. ANN. tit. 18 § 9701(5) (West 2015).

141. See VT. STAT. ANN. tit. 18 § 1871(b) (West 2014) (“A patient with a terminal illness has the right to be informed by a clinician . . .”).

142. See *supra* Part III.B.

143. Anthony L. Back, *supra* note 87, at 668 (“The . . . team [of experts] should take responsibility for initiating conversations about goals of care with [the patient] . . . because of their current knowledge of . . . [the patient’s] clinical status, their subspecialty-level knowledge of the disease trajectory, the trust they have built with . . . [the patient], and their moral duty not to abandon the patient at the end of life.”).

In keeping with its other vague qualities, section 1871 does not define “terminal illness.” The only relevant definition under Title 18 is in section 5281, Vermont’s Patient Choice and Control at End of Life law, under which a terminally ill patient with his judgment intact may request a self-administered lethal dose of medication from his physician.<sup>144</sup> Importantly, section 5281 starts, “[a]s used in this chapter: . . .” which means that this definition of “terminal illness” is instructive, but by no means controlling, as it is from a different chapter. There, “terminal illness” is defined as “an incurable and irreversible disease which would, within reasonable medical judgment, result in death within six months.”<sup>145</sup> The first half of this definition is uniquely straightforward: “incurable and irreversible,” implying that the six-month timeline is, to use New York’s wording, “whether or not treatment is provided,” since “incurable” suggests that curative treatments will have no effect. The second half, however, returns Vermont to its position of overt vagueness. By way of example, in the case of a pancreatic cancer patient, one could argue that chemotherapy is a curative-based treatment for cancer, and that if he undergoes such treatment, there is a greater chance that he might outlive his six-month prognosis than if he simply lets his cancer take its natural course. With that in mind, “incurable” and “six months, whether or not treatment is provided” are not synonymous.

California’s section 442.5 imposes the duty to provide palliative-care information only “[w]hen a health care provider makes a diagnosis that a patient has a terminal illness . . . .”<sup>146</sup> At first glance, this appears to be the narrowest identification criteria for a provider governed by such a palliative-care law. It seems that the mandated provider is only the one who makes the diagnosis, and not a different, follow-up provider; but also that the diagnosing provider must hold the mandated conversation at the time of diagnosis, and not a later, follow-up visit. That situation would also imply that if, for reasons based on the clinical standards and the patient’s reaction to the diagnosis, the practitioner does not

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144. VT. STAT. ANN. tit. 18 §§ 5281–5292 (West 2013).

145. *Id.* § 5281(10) (Section 5281 is the “Definitions” section of the Patient Choice law.).

146. CAL. HEALTH & SAFETY CODE § 442.5(a) (West 2015). See CAL. HEALTH & SAFETY CODE § 442(c) (West 2009) for a definition of “health care provider” as an “attending physician and surgeon.”



provide the information at this initial visit, then no one after him is ever mandated to inform the patient of his rights.

However, a closer look demonstrates that this is fortunately not the case. Section 442.5(a)(1) adds, “This notification may be provided at the time of diagnosis or at a subsequent visit in which the provider discusses treatment options with the patient or the other authorized person.”<sup>147</sup> This clause indicates that the diagnosing provider need not overwhelm his patient with a speech, or pages, of additional information, when the patient is likely still attempting to process the fact that he has just received a terminal prognosis. In fact, the clause appears to encourage multiple conversations occurring over series of visits, which is the ideal method for offering advance care-planning conversations.<sup>148</sup> A patient approaching kidney failure might appreciate hearing what his options are, outside of dialysis and transplant; or he might rather return for a second visit with his spouse or other family, for emotional, intellectual, or other support in deciding whether he wants to artificially extend his life or improve his quality of death. A patient with a recent cancer diagnosis, on the other hand, might want to hear all of the information that the practitioner can give him at the time of diagnosis, so that he can make an informed decision on his own. From the other side, an Alzheimer’s patient’s practitioner may not want to repeat himself, and so may request that the patient return with an “authorized person” to hear the palliative-care information along with the patient, himself.<sup>149</sup>

New York’s law uses much more general language when identifying the practitioner governed under the statute, and does not address whether the informing practitioner must also be the diagnosing practitioner. Relatedly, New York does not specify that, if the information is not provided at time of diagnosis, then it can be raised at a later visit. Rather, in New York, any “attending” practitioner who encounters a terminally ill patient is required to inform the patient of his right to learn about his palliative-care

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147. CAL. HEALTH & SAFETY CODE § 442.5(a)(1) (West 2015).

148. See *supra* Part II.

149. See CAL. HEALTH & SAFETY CODE § 442.5(e) (West 2015) (“If the patient or other authorized person requests information . . .”).

options (or arrange for someone else to provide this information).<sup>150</sup>

At the end of California's section 442.5(d), the legislators added that the required counseling may take place "with the health care provider *or others who may be providing the information and counseling based on the patient's needs.*"<sup>151</sup> California's law is the first to acknowledge what Tolle, Back, and Meier have also astutely pointed out: while the patient's diagnosing practitioner may be the most familiar with the patient and his needs, that is not always the case, and there are often times when a non-diagnosing medical specialist or palliative-care team are the most appropriate practitioners to hold the conversation.<sup>152</sup> By adding this one clause, California's law becomes the broadest of all. The law encourages each physician who addresses the patient's needs to counsel the patient, ensuring at least some information from every practitioner.

California offers all physicians an explicit opt-out from this duty in section 442.7. The section starts out straightforwardly with the words, "If a health care provider does not wish to comply . . . ."<sup>153</sup> It goes on to instruct the unwilling health care provider to refer or transfer the patient to someone who will provide the patient with any requested information and to explain to the patient how he can transfer to the other specified provider.<sup>154</sup> The New York State Assembly took care two years after the Information Act's passage to add the words "or does not feel qualified" to the category of practitioner that may avoid the mandate.<sup>155</sup> California's lawmakers seem less interested in the reason behind the practitioner's desire not to counsel his patient and more concerned with ensuring that the patient receives adequate and appropriate counseling.

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150. Information Act, N.Y. PUB. HEALTH LAW §§ 2997-c(2)(b), 2997-c(3) (McKinney 2013).

151. CAL. HEALTH & SAFETY CODE § 442.5(d) (West 2015) (emphasis added) (embedded in the section of the law discussing the "counseling" aspect of the required conversation, rather than the "information-providing" aspect).

152. Diane E. Meier, *supra* note 104 ("The complexity and intensity of [the patient's] . . . needs and the widely recognized inability of traditional medicine to meet them are the reasons for the rapid growth of the new field of palliative medicine."). *See also* Anthony L. Back, *supra* note 87.

153. CAL. HEALTH & SAFETY CODE, *supra* note 147, § 442.7.

154. CAL. HEALTH & SAFETY CODE, § 442.5(a)(2) (West 2009).

155. Information Act, *supra* note 150, § 2997-c(3) (2013) (adding the clause "or does not feel qualified" to clarify that while a physician may be willing to hold a conversation, feeling unqualified to do so eclipses the importance of that willingness).

Adding to a broadness that rivals Vermont's, California does not define "terminal illness" in any part of its health code. Section 442, the "Definitions" section of the End-of-Life Care part, defines "actively dying" as "the phase of terminal illness when death is imminent."<sup>156</sup> From this, California practitioners can extrapolate that "terminal illness" does not require "imminent" death, a term that is similarly unclear. Between Vermont's and California's paucity of definitions, it becomes clear that New York's unclear timeline, and exploration of the effect of treatment on it, together provide a framework on which practitioners can depend, though the value of such reliance may be questionable.

#### B. INFORMATION REQUIRED UNDER MICHIGAN, VERMONT, AND CALIFORNIA LAW

The form and content of advance care-planning conversations, as required under the laws of Michigan, Vermont, and California, differ greatly from New York's, though in varying degrees. Michigan lays out detailed instructions that culminate in an instruction for the Michigan Department of Community Health to author a written guide for practitioners holding these conversations.<sup>157</sup> Vermont, as expected, has the broadest and arguably most vague imposition on practitioners.<sup>158</sup> California is unique in that the patient's right to substantive information is only triggered when the patient asks.<sup>159</sup>

Michigan details an intricate process by which a practitioner must discuss his patient's terminal illness and treatment options. Section 333.5654 of the Public Health Code instructs the practitioner to orally inform his patient about the recommended medical treatment and its alternatives, as well as the "advantages, disadvantages, and risks" of each treatment or procedure.<sup>160</sup> By the context of the section, "alternatives" is understood to mean palliative care options, if palliative care is not the foremost recommended treatment. Alternatively, palliative care may be one

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156. CAL. HEALTH & SAFETY CODE, *supra* note 147, § 442.5(a) (West 2009).

157. MICH. COMP. LAWS ANN. §§ 333.5656 (West 2002).

158. VT. STAT. ANN. tit. 18 § 1871(b) (West 2014) (requiring clinicians to explain "all available options related to terminal care").

159. CAL. HEALTH & SAFETY CODE, *supra* note 147, § 442.5(a)(2) ("Upon the request of the patient . . . provide the patient . . . with comprehensive information and counseling . . .").

160. MICH. COMP. LAWS ANN., *supra* note 157, §§ 333.5654(1)(a)–(b).

of the recommended therapies. Section 333.5654(2) limits the required disclosure to that which adheres to “the applicable standards of practice.”<sup>161</sup>

In addition to verbally outlining recommended treatments, section 333.5655 requires the practitioner to advise the patient, both orally and in writing, about the patient’s options regarding designating a surrogate decision-maker, his right to make informed decisions about “life-sustaining treatment,” his right to choose palliative or hospice care instead of curative treatments, and his right to pain medication as a “basic and essential element” of medical treatment.<sup>162</sup> The Michigan legislature does not demand that practitioners remember all of these requirements or invent new ways of advising their patients in every meeting. Instead, the legislature charged the state’s Department of Community Health with publishing and making readily available to all physicians a “standardized, written summary of all the information required under section 5655.”<sup>163</sup> The summary is intended not only for the practitioner’s education and ease of communication, but also for the patient to read for himself.<sup>164</sup> The current, updated Michigan Physician Guide to End-of-Life Care is a 47-page patient-centric and user-friendly manual that opens by emphasizing values such as communication, dignity, and collaboration between all parties involved.<sup>165</sup> Finally, section 333.5657(1) clarifies that if a practitioner hands the patient, or his representative, the Michigan Physician Guide, he is considered to be “in full compliance” with section 333.5655’s requirement to educate the patient on his options other than the recommended treatment.<sup>166</sup>

The required content in conversations governed by the Information Act, while expressed differently than in Michigan’s laws, gets a similar point across. The major difference between the Information Act and Michigan’s laws is the way in which the practitioner must or may communicate the information. The

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161. *Id.* § 333.5654(2).

162. *Id.* §§ 333.5655(a)–(d).

163. *Id.* § 333.5656(1).

164. *Id.* § 333.5656(2) (“The department shall draft the summary in nontechnical terms that a patient . . . can easily understand.”).

165. MICH. STATE MED. SOC’Y, MICHIGAN PHYSICIAN GUIDE TO END-OF-LIFE CARE 1 (2010).

166. MICH. COMP. LAWS ANN., *supra* note 132, § 333.5657 (“If a physician gives a summary of the standardized, written summary . . . the physician is in full compliance with the requirements of section 5655.”).

clearest difference is that while the Information Act states simply that the practitioner “shall offer to provide the patient with” palliative-care-related information “orally or in writing,” Michigan’s laws articulate what information is expected in writing and what can merely be spoken.<sup>167</sup> Michigan is also unique in authorizing the physician to provide written-only guidance.<sup>168</sup>

The practical difference is striking. For any patient, discussing a terminal illness and end-of-life care can be a shock, and oral information regarding the complexities of different treatment options may not stick in a patient’s memory. Yet Michigan’s assent to physician compliance with the mandate to educate the patient about palliative and end-of-life options without any conversation at all also has its drawbacks. The patient may misunderstand the purpose of the document, assuming either that it is entirely irrelevant to his situation or that the physician is forcing the patient to forego curative therapies. Someone with a diagnosis of Alzheimer’s disease may require more than what New York requires; a classic symptom of Alzheimer’s disease is the fading of short-term memory capabilities, and it may be too difficult for such a patient to decipher everything he hears. At the same time, he may be overwhelmed if his practitioner simply hands him a hurriedly described booklet and does not give the patient enough time to process the booklet’s purpose.

In Vermont, the statutory language is much less specific than either New York or Michigan. Section 1871(b) simply states that a terminally ill patient has “a right to be informed . . . of all available options related to terminal care,” to request any of those options, and to receive “supportive care” for whatever the patient chooses.<sup>169</sup> Vermont’s syntax is patient-centric, that is, it establishes quickly and firmly that the purpose of requiring a clinician to provide this information is to fulfill the patient’s right to this information. It only minimally intrudes on the clinician-patient relationship, as it establishes that the patient has a right to this

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167. Contrast N.Y. PUB. HEALTH LAW § 2997-c(2) with MICH. COMP. LAWS ANN. §§ 333.5654(1)(a)–(b) (a physician shall “(a) orally inform the patient . . . about the recommended medical treatment . . . and (b) orally inform the patient . . . about the advantages, disadvantages, and risks . . .”) and MICH. COMP. LAWS ANN. §§ 333.5655 (“In addition to the requirements of section 5654,” a physician “shall, both orally and in writing, inform the patient of all of the following . . .”).

168. MICH. COMP. LAWS ANN. §§ 333.5657 (“If a physician gives a copy of the standardized, written summary . . . to a patient . . . the physician is in full compliance with the requirements of section 5655.”). See *supra* note 166.

169. VT. STAT. ANN. tit. 18 § 1871(b) (West 2014).

information, but does not oblige the clinician to present the information in any particular manner. Its broad reference to “all available options related to terminal care” sets a high standard for the amount of information the clinician must be willing and able to convey. However, within those wide bounds, there is a significant amount of space for the clinician’s own professional judgment. Implicit in Vermont’s law, as is generally the case with licensed professions, is the caveat that where the law mandates “all information,” it means, as New York’s explicitly states, that which is “appropriate to the patient.”<sup>170</sup> In other words, the patient does not have the right to a lesson in general end-of-life care; he has a right to those types of care that are applicable to his personal situation. This could amount to a general lesson on end-of-life care as it pertains to a patient’s overall health, since the practitioner cannot know with certainty what courses the illnesses will take. For a diabetic patient approaching kidney failure, this might mean a full explanation about dialysis, kidney transplant, and solely palliative therapy, at first; but once he decides on a treatment plan, future discussions will focus solely on that chosen plan, until the next time his health worsens. On the other hand, so little is known about Alzheimer’s disease prognoses that the clinician can summarily, gently, explain that there is no cure to pursue, and focus on palliative care and symptom management, rather than an elaborate discussion about the history of Alzheimer’s therapies.

California’s section 442.5 is the clearest about attempting to strike a balance between obligating certain topics of conversation and providing support for the practitioner when he needs it. First, the law requires only that the practitioner inform the patient of his “right” to “comprehensive information and counseling regarding legal end-of-life options.”<sup>171</sup> The real substance of the conversation is only mandated “upon the request of the patient.”<sup>172</sup> As an unfortunate result, the information to which the patient has a right may not even arise for patients who are too

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170. Information Act, N.Y. PUB. HEALTH LAW § 2997-c(2)(a) (McKinney 2013) (demonstrating that “appropriate to the patient” is considered in the context of describing how much information the practitioner must provide to any given patient). This is implicit and generally accepted because the alternative, requiring practitioners to provide information on every slight possibility of treatment, would lead to absurd results.

171. CAL. HEALTH & SAFETY CODE § 442.5(a)(1) (West 2015).

172. *Id.* § 442.5(a)(2).

confused or afraid to ask the right questions.<sup>173</sup> Section 442.5(e) emphasizes that any information the practitioner provides must be given in a “culturally sensitive manner,” which may explain the law’s acquiescence to the practitioner waiting for the patient to ask for greater detail about palliative and end-of-life options.

California also uniquely describes the way in which this catalog of information may be communicated. Section 442.5(c) notifies the practitioner that the information “may, but is not required to, be in writing.”<sup>174</sup> Furthermore, as subsection (c) continues, California allows practitioners to utilize written information, from the Internet or otherwise, created by “organizations specializing in end-of-life care.”<sup>175</sup> As with Michigan’s law, this ability for Californian practitioners to use ready-made “fact sheets” takes a significant amount of pressure off the practitioners, because they do not need to conjure exactly which details to share and how to share them. Even with the ability to go to any end-of-life organization, the information that the practitioner will provide is likely more standardized than if the California State Legislature had charged him with inventing his own explanations, as there are only so many websites. By the law’s reference to “factsheets,” this also seems to imply that the practitioner should have written information available to his patient, even if such a method is not required by the law.<sup>176</sup>

California is the only state to call attention to the patient’s potential interest in the cost of his treatment options, “including the availability of insurance and eligibility of the patient for coverage.”<sup>177</sup> California’s law, effective January 1, 2015, is in line with the current trend of bearing in mind the cost of patient care, even if finances do not end up as a determinative factor for the patient.<sup>178</sup> Even for patients with insurance, co-pays and deducti-

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173. See SHARON R. KAUFMAN, *AND A TIME TO DIE* 34 (Scribner ed., 2005) (“[P]atients and families, when faced with health crises and the surrounding plethora of medical options, *do not know what to want*, other than recovery or an end to suffering in the general sense.”) (emphasis added).

174. CAL. HEALTH & SAFETY CODE, *supra* note 147, § 442.5(c) (describing the ways in which the practitioner might communicate the fairly itemized topics of information enumerated in subsection (b)).

175. *Id.*

176. *Id.* (“Health care providers may utilize information from organizations specializing in end-of-life care that provide information on fact sheets and Internet Web sites to convey the information . . .”).

177. *Id.* § 442.5(e) (emphasizing that information should be given in a “culturally sensitive manner . . . that the patient . . . can easily understand”).

178. See *supra* Part II.

bles can add up to prohibitively expensive sums, and prudent patients may want to learn about additional funding sources for expensive treatments.

California's statute may also be indicative of another general trend. Before the newest version that became effective in 2015, the law read, "the health care provider shall, upon the patient's request, provide the patient with comprehensive information and counseling . . ." <sup>179</sup> This previous version thus mandated advance care-planning only if the patient already knew to ask for information regarding palliative-care treatment options. Patients having such knowledge are no longer the focus of these laws. <sup>180</sup> Rather, the trend evinced by the other states' laws is that the physician is required to attempt to initiate palliative-care discussions with terminally ill patients. <sup>181</sup> As such, one of the few changes to California's revised statute is to insist that the practitioner, at a minimum, alert his patient to the patient's right to information regarding palliative care, though he need only continue down that line of conversation if the patient requests it. <sup>182</sup> The concern that would have led California's lawmakers to this revision is that someone with advanced diabetes may not realize that diabetes, when untreated, fits most standard definitions of "terminal illness," and so he may not know to bring up palliative care as a possible therapy.

### C. ENFORCEMENT ACTION AGAINST PHYSICIAN NON-COMPLIANCE IN MICHIGAN, VERMONT, AND CALIFORNIA

Generally speaking, the failure of a practitioner to adhere to expected, statutory conduct is considered a misdemeanor. <sup>183</sup> The consequences of statutory breach, though, vary between states, based on the relevant enforcement statutes. Under Michigan's

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179. CAL. HEALTH & SAFETY CODE § 442.5 (West 2010). This version was effective from 2010 through 2014, and was directly replaced by the current version, effective Jan. 1, 2015.

180. See KAUFMAN, *supra* note 173, at 34 ("[P]atients and families, when faced with health crises and the surrounding plethora of medical options, *do not know what to want*, other than recovery or an end to suffering in the general sense.") (emphasis added).

181. Information Act, N.Y. PUB. HEALTH LAW § 2997-c(2) (McKinney 2013); MICH. COMP. LAWS ANN. § 333.5657(3) (West 2002).

182. CAL. HEALTH & SAFETY CODE, *supra* note 147, § 442.5(a)(1) ("[n]otify the patient of his or her right . . . to comprehensive information and counseling. . .").

183. There is no case law that cites to the right-to-information laws of Michigan, Vermont, and California, discussed in this Note.



statutes, practitioners can take steps to immunize themselves against accusations of failing to hold advance care-planning conversations.<sup>184</sup> Vermont's health code simply lays out the penalty for violations;<sup>185</sup> its penal code describes the offense as a misdemeanor.<sup>186</sup> California's statute states that violating its statutes through "unprofessional conduct" is a misdemeanor and describes the penalty.<sup>187</sup>

Michigan's Public Health Code enforcement statute states clearly: "a person who violates . . . this article . . . is guilty of a misdemeanor . . ."<sup>188</sup> However, the Code also provides a very detailed and intricate process to establish administratively whether a violation has occurred, and if so, what the penalty should be. The Michigan Department of Licensing and Regulatory Affairs oversees disciplinary actions through its disciplinary committee and is charged with investigating allegations of violations of sections 333.5654 and 333.5655.<sup>189</sup> The complaint needs to allege a violation of only one of these sections, not both, to trigger an investigation. If the disciplinary committee finds that either one of these sections has been violated, it may impose "reprimand, probation, suspension, revocation, permanent revocation, or fine."<sup>190</sup> This penalty went into effect March 30, 2015, and is

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184. MICH. COMP. LAWS ANN. § 333.5657(3) (West 2002) ("A patient . . . who signs a form under subsection (2) is barred from subsequently bringing a civil or administrative action . . . based on failure to obtain informed consent."). The "form under subsection (2)" states that the practitioner has complied with the terms of §§ 333.5654 and 333.5655. *Id.* § 333.5657(2).

185. VT. STAT. ANN. tit. 18 § 131(a) (West 1985) ("Any person who violates a provision of this title . . . shall be fined not more than \$5000.00.").

186. VT. STAT. ANN. tit. 13 § 1 (West 1973) (After describing felonies, the statute states, "[a]ny other offense is a misdemeanor.").

187. CAL. BUS. & PROF. CODE § 2314(a) (West 2008) (stating that a violation of the enforcement article is a misdemeanor); CAL. BUS. & PROF. CODE § 2315(a) (West 2011) (explaining that the punishment of a misdemeanor shall be a fine or term of imprisonment or both).

188. MICH. COMP. LAWS ANN. § 333.16299(1) (West 2013). *See also* MICH. COMP. LAWS ANN. § 333.1299(1) (West 2005) (stating that a person who violates a provision of the Public Health Code for which no penalty is provided shall be guilty of a misdemeanor). It appears that such prosecutions are extraordinarily rare, if occurring at all.

189. MICH. COMP. LAWS ANN. §§ 333.16104(3), 333.16104(5) (West 2011) (delineating the practitioner's verbal-communication requirement); MICH. COMP. LAWS ANN. § 333.16221(p) (West 2015) (describing the verbal and writing components in tandem). Subsection (p) establishes "A violation of section 5654 or 5655" as grounds for disciplinary action. *Id.*

190. *Id.* § 333.16226(1) (imposing the same sanctions as those for violations of subdivisions (k) and (r) of § 333.16221). It is not immediately clear why the state imposed these harsher punishments.

significantly harsher than its predecessor, which imposed solely “reprimand or fine.”<sup>191</sup>

Complainants in Michigan may also allege a “violation of general duty” rather than of the specific sections of the code.<sup>192</sup> If the practitioner is found guilty under such an accusation, the sanctions may include “Probation, limitation, denial, suspension, revocation, permanent revocation, restitution, or fine.”<sup>193</sup>

There are two primary differences between Michigan’s allegations of violating “general duty” and the specific provisions involved in the patient’s right to information regarding palliative care. First, a case in which a provider neglects his “general duty” to a patient<sup>194</sup> is determined to be so ruinous that “reprimand” is not even an option, though it is an option for violating sections 333.5654 and 333.5655.<sup>195</sup> Second, the disciplinary committee may impose a fine up to \$250,000 for a “general duty” allegation, but not the others.<sup>196</sup>

With such severe penalties in place, the Michigan legislature also provides physicians with immunity against certain administrative and civil actions in the end-of-life care context.<sup>197</sup> When a practitioner holds the required advance care-planning conversation with his patient, or provides the patient with the Michigan Physician Guide to End-of-Life Care, he may also ask the patient to sign a form indicating that the patient has received this oral and written guidance.<sup>198</sup> If the patient signs the form, the physi-

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191. MICH. COMP. LAWS ANN. § 333.16226 (West 2014) (amended 2015) (imposing the same sanctions as those for violations of subdivisions (k) and (r) of § 333.16221, as in the newer version).

192. MICH. COMP. LAWS ANN. § 333.16221(a) (West 2015) (“(a) . . . [A] violation of general duty, consisting of negligence or failure to exercise due care . . . whether or not injury results . . .”).

193. MICH. COMP. LAWS ANN. § 333.16226(1) (West 2015).

194. MICH. COMP. LAWS ANN. § 333.16221(a) (West 2015) (“ . . . a violation of general duty, consisting of negligence or failure to exercise due care. . .”).

195. See *supra* note 190.

196. MICH. COMP. LAWS ANN. § 333.16226(3) (West 2015) (“A disciplinary subcommittee may impose a fine that does not exceed \$250,000.00 for a violation of section 16221(a) or (b).”). Subsection (b) relates to “personal disqualifications,” such as incompetence or conviction of certain criminal offenses.

197. MICH. COMP. LAWS ANN. § 333.5657(3) (West 2002) (“A patient . . . who signs [the] form . . . is barred from subsequently bringing a civil or administrative action against the physician for providing the information orally and in writing under section 5655 based on failure to obtain informed consent.”).

198. *Id.* § 333.5657(2). This subsection also clarifies that, as with the rest of the law, if the patient is unable to sign such a form, then his representative or advocate should sign in his place. *Id.*

cian then places a copy in the patient's medical record.<sup>199</sup> This signed form establishes an evidentiary record in the practitioner's favor that the required conversations took place. A patient who signs this form is barred from bringing a civil or administrative action against his provider regarding the validity of the form.<sup>200</sup>

The procedure in place in Vermont is not as complex as that in Michigan, but does provide some pointed guidance. The Vermont Board of Medical Practice within the state's Department of Health investigates civil complaints regarding "unprofessional conduct" by licensed clinicians.<sup>201</sup> The board may wait for private individuals to file written complaints, or it may act "on its own initiative."<sup>202</sup> "Unprofessional conduct" in Vermont includes the failure to comply with state statutes "governing the practice of medicine."<sup>203</sup> If the Board feels that the clinician's actions were unprofessional but do not fit into any of the listed categories, then it may find that "failure to conform to the essential standards of acceptable and prevailing practice" constitutes punishable "unprofessional conduct."<sup>204</sup> If the Board finds the clinician guilty of the alleged "unprofessional conduct," the Board may reprimand the clinician; "condition, limit, suspend, or revoke" the clinician's license; or "take such other action" that the Board deems "proper."<sup>205</sup> This "other action" may include the imposition of a fine of up to \$1000 for each violation.<sup>206</sup>

In addition to civil disciplinary actions available to the Board, the state may choose to charge the practitioner with a criminal violation. Because the only punishment for violating these

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199. *Id.* Presumably, the patient can take a copy home, as well, which is why the section says "place a copy of the signed form in the patient's medical record" and not that the original and only copy must remain in the medical record. *Id.*

200. *Id.* § 333.5657(3) ("A patient . . . who signs [the] form . . . is barred from subsequently bringing a civil or administrative action against the physician for providing the information orally and in writing under section 5655 based on failure to obtain informed consent."). The law does not address whether the state may bring its own action against the practitioner.

201. VT. STAT. ANN. tit. 26 § 1351(a) (West 2015); VT. STAT. ANN. tit. 26 § 1353(2) (West 2014).

202. VT. STAT. ANN. tit. 26 § 1355(a) (West 2011).

203. *Id.* § 1354(a)(27) (within a list of 39 particular examples of "unprofessional conduct").

204. *Id.* § 1354(b)(2) (listing this as one way of failing "to practice competently by reason of any cause on a single occasion or on multiple occasions").

205. *Id.* § 1361(b) (West 2011).

206. *Id.* The section states that the money collected from these fines will go to education and training for board members and licensees. *Id.*

standards is a monetary fine, the violations are considered misdemeanors.<sup>207</sup>

California's laws are organized somewhat differently. The Medical Practice Act constitutes Chapter Five of the Business & Professions Code.<sup>208</sup> The Practice Act's provisions are executed and enforced by the Medical Board of California, a division of the Department of Consumer Affairs,<sup>209</sup> but the actual disciplinary hearings are conducted by administrative law judges of the Medical Quality Hearing Panel.<sup>210</sup> These provisions include a definition of "unprofessional conduct," which may mean, among other things, incompetence or gross negligence.<sup>211</sup> Incompetence and gross negligence are two of the most common violations of professional conduct committed by physicians in California.<sup>212</sup> The Board is likely to find a physician incompetent if he lacks sufficient knowledge in an area, or may find him grossly negligent if he exhibits "an extreme departure from accepted standards of medical practice."<sup>213</sup> It is reasonable to conclude that in the circumstances governed by section 442.5, an "accepted standard" of practice for physicians who cannot or do not wish to comply, would be to follow the steps provided in section 442.7. An extreme departure from the norm in California, then, may exist if a practitioner preferred violating section 442.5 instead of using the simple "bailout" provision contained in section 442.7.

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207. VT. STAT. ANN. tit. 13 § 1 (West 1973) ("[A]ny offense whose maximum term of imprisonment is more than two years . . . is a felony. Any other offense is a misdemeanor."). *But see* VT. STAT. ANN. tit. 26 § 1368 (West 2015) (describing felonies and "serious" misdemeanors, with the implication that there are unofficially two types of misdemeanors, those that are serious, and those that are not serious).

208. Medical Practice Act, CAL. BUS. & PROF. CODE §§ 2000–2029 (West 1980).

209. *Id.* §§ 2001(a), 2004(a).

210. CAL. GOV'T CODE § 11371 (West 2006) (establishing the Medical Quality Hearing Panel); CAL. GOV'T CODE § 11372(a) (West 2008) (clarifying that all adjudicative hearings regarding disciplining licensees of the Medical Board of California, heard pursuant to the Administrative Procedures Act, shall be presided over by an administrative law judge).

211. CAL. BUS. & PROF. CODE §§ 2234(b), 2234(d) (West 2014).

212. MED. BOARD OF CAL., INFORMATION AND SERVICES FOR CONSUMERS 1 (2009) (According to the Medical Board, the other most common violation is "repeated negligent acts.").

213. *Id.*

## V. RECOMMENDATIONS FOR ENFORCEMENT OF NEW YORK'S PALLIATIVE CARE INFORMATION ACT BASED ON OTHER STATES' APPROACHES

Each of the laws discussed in Parts II and III have defining qualities. Michigan essentially lays out a piecemeal template for practitioners involved in advance care-planning with terminally ill patients, up to and including the sanctions for violating the particular governing statute. At the other end of the spectrum is Vermont's one-line "patient bill of rights" mandate, which is the least intrusive on the clinician-patient relationship. At the same time, Vermont's law may be so vague as to become overbroad, ineffective, and practically unenforceable. Between these two lies California's statute, which fails to define the key term "terminal illness" yet acknowledges the authoritative role that practitioners other than the diagnosing physician may play in a patient's care plan.

This Part focuses on recommendations for methods of clarifying enforcement of the Palliative Care Information Act. It may well be true that each practitioner is aware of and can provide the most appropriate information for his patient, and for that reason, this Note does not suggest any additional affirmative mandates on practitioner speech. Adding provisions to expound on enforcement of the law will serve to delineate what has already been required of physicians, not simply since the passage of the Information Act, but since the introduction of the notion of informed consent. The law must be effective in promoting this vital concept without overly intruding on the practitioner's professional practice and judgment. It must balance firm discipline of non-compliant practitioners without imposing such broad and harsh punishments so as to deter others providers from working in this area of medicine.

The New York State Assembly should adopt a uniform evidentiary standard to determine whether the required advance care-planning conversation has taken place, rather than relying on subjective reports from practitioners or their patients. In addition, the Assembly should amend the Information Act, or draft an entirely new provision, to establish more realistic enforcement actions against practitioners who violate this type of law.

Despite the concern voiced by practitioners about legislative interference in the delicate physician-patient relationship, the

Information Act's mandate to educate one's terminally ill patients about all available options — that is, to ensure that one's patients are giving truly informed consent to curative or solely palliative therapies — is relatively unobtrusive when compared to alternatives.<sup>214</sup> The statutory restraint, however, goes so far as to be viewed by some as impossibly vague and difficult to implement.<sup>215</sup> The more practical apprehension raised by this latter point is that a physician may not have sufficient notice that he is violating the Information Act. A physician may have experience only with cancer patients with encouraging prognoses, and so may not fully understand the need for immediate, detailed information for a pancreatic-cancer patient with, in all likelihood, fewer than six months to live. At the other end of the spectrum, a diabetic patient may have heard so many success stories about dialysis that he may not even realize his physician is attempting to explain how palliative care applies to his end-stage renal disease. If either of these patients later learns about palliative and end-of-life care from another source, they may be inclined to file complaints with the Office of Professional Medical Conduct. For repeat offenses, the Office may involve the Attorney General, and the physician could be required to pay a hefty fine without even realizing he has broken a law. A practitioner's notes scribbled in his patient's chart as he prepares for his next appointment may be instructive or introduced as evidence of his attempts to provide comprehensive palliative-care information, but they are not determinative of the exact interaction that occurred.

The evidentiary standards indicated in Michigan's sections 333.5656 and 333.5657 are one possible solution to this comprehension problem.<sup>216</sup> Section 333.5656 resulted in the development of the Michigan Physician Guide to End-of-Life Care, a standardized summary published by the Michigan Department of Community Health and made available to all Michigan physi-

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214. See FLA. STAT. ANN. § 790.338 (West 2011) (prohibiting practitioners from asking their patients if they own firearms unless the practitioner believes, in good faith, that the information is relevant to the patient's medical care or safety). *But see* Mary Rappazzo, *supra* note 90 (arguing that the burden imposed by the Information Act equals that of Florida's § 790.338 because they both intrude on the physician-patient relationship).

215. Astrow & Popp, *supra* note 89, at 1885 (discussing the problem of the vagueness of the "terminal illness" focus of the law).

216. MICH. COMP. LAWS ANN. § 333.5656 (West 2002) (describing the booklet published by the Department of Community Health); MICH. COMP. LAWS ANN. § 333.5657 (West 2002) (describing the steps a practitioner must take to explain and provide the patient with the booklet).

cians.<sup>217</sup> The benefits of Michigan's system here are clear. During the meeting, there is no question about whether a physician has satisfied his burden of providing the patient with written information on palliative and end-of-life care, because the law requires him to hand his patient a 47-page booklet with the words "Guide to End-of-Life Care" on the cover. The Information Act already allows for the practitioner to provide this information "orally or in writing," so the change would not drastically alter the physician-patient interaction.<sup>218</sup> If anything, the standardized document may help the practitioner discuss a delicate topic, and its patient-centric words may aid the patient in understanding his options and communicating his concerns.

The New York Assembly should amend the Information Act to include a provision directing the state Department of Health to create a similar booklet for New York practitioners. The Department's website contains a list of resources for practitioners, but the websites listed there vary widely in style, intended audience, and functionality.<sup>219</sup> A "New York Physician Guide to End-of-Life Care" available on the website and in practitioners' offices would increase the chances that practitioners and their patients have a common understanding of how to approach discussions of palliative and end-of-life care.

However, in requiring only that the practitioners hand the patient this document, the law would do little to help a practitioner who is nonetheless accused of violating the terms of the law, because he would be left with the same negligible amount of proof after handing his patient the guide. Michigan's answer to this particular issue lies in its section 333.35657, in requiring patients to sign a form attesting to their participation in a palliative or end-of-life care conversation.<sup>220</sup> At the end of the appointment, the practitioner must still rely on his patient's medical record for evidence of a palliative-care conversation. The informed consent form, once it is signed and placed in the patient's record, creates

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217. See *supra* Part III.B.

218. Information Act, N.Y. PUB. HEALTH LAW § 2997-c(2)(b) (McKinney 2013) (describing the ways in which a practitioner may communicate information regarding both palliative and curative options, where applicable).

219. N.Y. STATE DEPT OF HEALTH, RESOURCES FOR PRACTITIONERS (2013), [http://www.health.ny.gov/professionals/patients/patient\\_rights/palliative\\_care/practitioners/resources.htm](http://www.health.ny.gov/professionals/patients/patient_rights/palliative_care/practitioners/resources.htm) [<http://perma.cc/4ZQ3-3GDJ>].

220. MICH. COMP. LAWS ANN. § 333.5657(2) (West 2002). See *supra* Part III.C.

an evidentiary record in favor of the practitioner's compliance with the Information Act.

Michigan's law states explicitly that the form is to be signed only after the patient has received his Guide to End-of-life Care, so that the patient can affirm that he has received both oral and written information.<sup>221</sup> There is no need for New York to follow so closely in Michigan's footsteps. While it makes sense for the Guide and the consent form to be presented together, there is no need for the patient to receive both. Different patients, or even the same patients over time, may differ in how they retain information.<sup>222</sup> New York could prompt its practitioners, as Michigan does, to request that their patients sign the form when appropriate, without attaching any other requirements. The patient need only have participated in a conversation regarding the patient's palliative-care or end-of-life options.

As has become clear, enforcing the Information Act and disciplining practitioners who do not comply with the law can become a convoluted process. First, there is the distinct lack of evidence to establish whether a conversation has happened. Second, the penalty for violating the Act — a prison term or a fine of up to \$10,000 — appears draconian.<sup>223</sup> This is because the State Assembly means for this enforcement provision, section 12-b, to apply to the entire Public Health Law. Indeed, there is no case law related to section 2997-c, and given the form that such a violation would take, it is unlikely that the complainant would go beyond the Office of Professional Medical Conduct's administrative disciplinary proceedings.

The New York Assembly should also amend the Information Act, or introduce a new provision, with more tailored enforcement clauses that more accurately and realistically reflect what a practitioner faces in violating section 2997-c and related laws. Section 12-b is indeed necessary for actions or behaviors that put the public health at immediate risk. But it contains that telling phrase, "the punishment for violating which is not otherwise prescribed by this chapter or any other law," which suggests that it

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221. MICH. COMP. LAWS ANN. § 333.5657(2) (West 2002) ("A physician may make available to a patient . . . a form indicating that the patient . . . has been given . . . a copy of the updated standardized, written summary . . .").

222. See *supra* Part III.B (explaining that a patient's Alzheimer's disease may render him unable to understand solely verbal instructions, while still requiring a verbal introduction to written documents).

223. N.Y. PUB. HEALTH LAW § 12-b(2) (McKinney 2014).



was written as a catch-all and not meant to apply to situations such as those involving the Information Act.<sup>224</sup>

Within its Public Health Code, the Michigan state legislature provides the exact administrative sanctions that practitioners face in violating specific provisions of that Code.<sup>225</sup> The list of possible sanctions is lengthy but simple and repetitive. The structure of the provision greatly increases the chances that practitioners are on notice about the possible consequences of violating the palliative-care information mandates. New York's public health law does include a penalizing provision similar to Michigan's,<sup>226</sup> but New York's version applies equally to all medical misconduct, ranging from violations of section 2997-c to putting lives in imminent danger. By introducing a new clause to section 2997-c that supersedes section 12-b, the State Assembly may be able to assuage some of the concerns raised by practitioners regarding the law's vagueness.<sup>227</sup> This addition could incorporate section 230-a by reference, thereby maintaining the same notice standards that practitioners already have for any other health code violation.

## VI. CONCLUSION

In 2010, New York took a major step in transforming the way that health care is delivered throughout the state. As often happens with such upheavals, the controversial Palliative Care Information Act was attacked as too broad, too vague, and too demanding.<sup>228</sup> These criticisms notwithstanding, the Information Act may still have the potential to improve the ever-tenuous

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224. *Id.*

225. *See, e.g.*, MICH. COMP. LAWS ANN. § 333.16226(1) (West 2015) (addressing each of several dozen possible statutory violations).

226. N.Y. PUB. HEALTH LAW § 230-a (McKinney 2008). This section, titled "Penalties for professional misconduct," details nine possible penalties that the Office of Professional Medical Conduct may impose on a practitioner found guilty of professional misconduct. *Id.*

227. Mary Rappazzo, *supra* note 90 ("This new law is very vague and almost impossible to interpret let alone implement.").

228. Astrow & Popp, *supra* note 89, at 1886–87 (2011) ("[P]hysicians need to feel comfortable communicating their own values and experiences and providing nonauthoritarian guidance and support while expressing interest in and respect for the experience and values of patients and families."). *See also* Mary Rappazzo, *supra* note 90 ("This new law is very vague. . ."); Memorandum from the State of N.Y. Dep't of Health to the N.Y. State Assembly, *supra* note 92. This memorandum points out that the definition of "terminally ill" is too broad because people with diabetes are not necessarily at the end of their lives.

practitioner-patient relationship by requiring open communication and truly informed consent when patients reach the point of terminal illness.<sup>229</sup>

Through exploring the array of techniques intended to educate patients about their right to appropriate palliative and end-of-life care, it may be possible to improve New York's Palliative Care Information Act. First, the State Assembly should charge the Department of Health with developing its own "written standardized summary" of the ideal series of advance care-planning conversations. The Assembly should also authorize practitioners to request their patients' signatures in affirmation of compliance with the Information Act's terms.

Discussions and care plans regarding death and dying are becoming more and more commonplace. Yet the notion of open and comfortable communication between practitioners and their patients about these topics is still an illusory goal. The Information Act is one controversial step toward improved relations between these parties. The suggestions in this Note are intended to mitigate the controversy surrounding the Information Act by providing advocacy for patients who want to see the law enforced and providing tangible support to practitioners when they, in turn, require it from the state.

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229. Information Act, N.Y. PUB. HEALTH LAW § 2997-c(2) (McKinney 2013).