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Volume 58

Issue 2 *Freedom of Choice at the End of Life:  
Patients' Rights in a Shifting Legal and Political  
Landscape*

Article 10

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January 2014

## **Health Justice Denied or Delayed at the End of Life: A Crisis Needing Remedial Action**

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### **Recommended Citation**

DAVID C. LEVEN, *Health Justice Denied or Delayed at the End of Life: A Crisis Needing Remedial Action*, 58 N.Y.L. SCH. L. REV. (2013-2014).

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## Health Justice Denied or Delayed at the End of Life: A Crisis Needing Remedial Action

58 N.Y.L. SCH. L. REV. 403 (2013–2014)

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## HEALTH JUSTICE DENIED OR DELAYED AT THE END OF LIFE

*The relief of suffering, it would appear, is considered one of the primary ends of medicine by patients and lay persons, but not by the medical profession.*<sup>1</sup>

### I. INTRODUCTION

Too many people die badly in this country. Too many people die suffering unnecessarily. And too many people do not have their health care wishes respected<sup>2</sup> at the end of life, which is one reason why people die badly. Health justice, in my view, entails receiving quality care and treatment to which patients are entitled, not receiving unwanted care and treatment, and having rights and decisions respected. Yet health justice is often denied to dying patients at one of the most difficult times for them and their families. It does not have to be this way. Changes are necessary and they can be made. Recent positive developments are encouraging, but more needs to be done, and more needs to be done now.

In Part II, I highlight concerns about dying and pain management. In Part III, I discuss issues pertaining to palliative care and how palliative care is moving upstream. In Part IV, I describe the denial of health justice for patients who are terminally ill and are prevented from making informed choices about critical health care decisions because health care practitioners fail to provide needed information. In Part V, I discuss new laws in New York designed to correct the problems of the lack of discussion about palliative care and end-of-life options, and the failure to provide timely palliative care—or any palliative care—in order to improve both best practices and patient care, and to ensure that patients' wishes are respected. These laws are models for the nation and should be enacted across the nation. In Part VI, I discuss the need for additional remedial legislation and summarize bills that are pending or to be proposed in the New York State Legislature which, if enacted, will improve health care training, foster better patient care, and generally improve and expand health justice for patients.

### II. DYING NOW AND THEN—PAIN AND SUFFERING

Much has changed in the way we die.<sup>3</sup> Today, unlike in the middle of the last century, when most people died relatively quickly, about seven out of ten deaths

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1. Eric J. Cassell, *The Nature of Suffering and the Goals of Medicine*, NEW ENG. J. MED. 639, 640 (1982). "The quote is still valid!" E-mail from Eric J. Cassell, M.D., to David Leven (Sept. 27, 2012) (on file with author). Dr. Cassell is a leading expert on the nature of suffering.
  2. Generally, patients with decisionmaking capacity have the right to accept or decline any medical treatment and to make informed decisions about their own care. Patients in health care institutions that receive Medicare or Medicaid funding must be informed in writing, upon admission, of (1) their right to accept or refuse treatment and (2) their rights under existing state laws regarding advance directives. See 42 U.S.C. § 1395cc (2013); see also *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261 (1990) (upholding the right of patients to refuse treatment); N.Y. PUB. HEALTH LAW § 2803(1)(g) (McKinney 2013) (requiring New York patients in hospitals to be provided with a Patients' Bill of Rights which indicates that they may refuse treatment).
  3. See David S. Jones, Scott H. Podolsky & Jeremy A. Greene, *The Burden of Disease and the Changing Task of Medicine*, 366 NEW ENG. J. MED. 2333 (2012), available at <http://www.nejm.org/doi/pdf/10.1056/>

among Americans each year are from chronic diseases; heart disease, cancer, and stroke account for more than 50% of those deaths.<sup>4</sup> We may be living longer, with life expectancy now close to eighty years<sup>5</sup> compared to about seventy years in 1960,<sup>6</sup> but we are not necessarily living better. In fact, many people now die sicker than in the past. Many chronically, seriously, and terminally ill patients have, among other things: poorly controlled symptoms, in particular, pain; psychiatric disorders and psychosocial and spiritual distress; concrete needs in the home; and challenges in care coordination, communication, decisionmaking, and goal-setting.

Pain is the most prevalent symptom which often causes great suffering. Yet, not nearly enough attention has been paid to pain and suffering in medical schools and by the medical profession. Although pain can largely be controlled, the undertreatment of pain is a serious public health crisis. There are many reasons, including: lack of training in medical and other professional schools; lack of postgraduate training; unfounded fears of physicians about prescribing opioid drugs; poor communication between physicians and patients; and lack of referrals to specialists when appropriate.

The undertreatment of pain is well documented.<sup>7</sup> The 2011 Institute of Medicine (IOM) report *Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education and Research*<sup>8</sup> found that “[c]urrently, large numbers of Americans receive inadequate pain prevention, assessment and treatment,”<sup>9</sup> even though there are approximately 100 million chronic pain sufferers in America, at a cost of \$560 to \$635 billion annually.<sup>10</sup> Regarding physician education, the IOM report stated:

The widespread prevalence of pain . . . demonstrates the need for medical educators to recognize it as a common and often severe condition. Yet there are strong indications that pain receives insufficient attention in virtually all phases of medical education—the lengthy continuum that includes medical school (undergraduate medical education), residency programs (graduate

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NEJMp111356; see also *Deaths and Mortality*, CTRS. FOR DISEASE CONTROL & PREVENTION, <http://www.cdc.gov/nchs/fastats/deaths.htm> (last visited Dec. 27, 2013) (indicating that almost 2.5 million people die annually in the United States).

4. See *Leading Causes of Death*, CTRS. FOR DISEASE CONTROL & PREVENTION, <http://www.cdc.gov/nchs/fastats/lcod.htm> (last visited Dec. 27, 2013).
5. See *Life Expectancy*, CTRS. FOR DISEASE CONTROL & PREVENTION, <http://www.cdc.gov/nchs/fastats/lifexp.htm> (last visited Dec. 27, 2013).
6. NAT'L CTR. FOR HEALTH STATISTICS, HEALTH, UNITED STATES, 2010, at 134 (2011), available at <http://www.cdc.gov/nchs/data/has/has10.pdf>.
7. See S. Deandrea, M. Montanar, L. Moja & G. Apolone, *Prevalence of Undertreatment in Cancer Pain: A Review of Published Literature*, 19 ANNALS ONCOLOGY 1985, 1985 (2008).
8. INST. OF MED. OF THE NAT'L ACADS., *RELIEVING PAIN IN AMERICA: A BLUEPRINT FOR TRANSFORMING PREVENTION, CARE, EDUCATION AND RESEARCH* (2011).
9. *Id.* at 7; see also Michael J. Fisch et al., *Prospective, Observational Study of Pain and Analgesic Prescribing in Medical Oncology Outpatients With Breast, Colorectal, Lung, or Prostate Cancer*, 30 J. CLINICAL ONCOLOGY 1980, 1980 (2012) (indicating that about one third of patients had their pain undertreated and twice as many minorities did not receive adequate pain management).
10. INST. OF MED. OF THE NAT'L ACADS., *supra* note 8, at 1.

## HEALTH JUSTICE DENIED OR DELAYED AT THE END OF LIFE

medical education), and courses taken by practicing physicians (continuing medical education [(CME)]).<sup>11</sup>

One would think that the teaching of pain management would be a priority in medical schools. It clearly is not, as indicated in the IOM report, and documented by a 2011 report which found that less than 4% of medical schools required a pain course and only 16% offered a pain elective.<sup>12</sup> The lack of training in pain management underscores the need for undergraduate and practicing health care professionals to receive mandatory training.

Regarding the provision of pain care, the IOM report noted that, “[a]lthough opioid analgesics are often indicated for chronic severe pain, people with such pain and institutions . . . can have difficulty obtaining them for various reasons. Sometimes it is a clinician’s reluctance to prescribe.”<sup>13</sup> The report commented on the difficulty patients have in obtaining opioids due to pressure on physicians to prescribe within the parameters of state and federal drug abuse prevention laws. This can impede effective pain management.<sup>14</sup> Consistent with the findings in the IOM report are findings in a 2005 Medical Society of the State of New York survey. It found that 75% of the New York doctors surveyed, who prescribed a controlled opioid drug to an outpatient with chronic pain, either occasionally or frequently prescribed a drug other than an opioid drug, even when an opioid drug was indicated. Of those surveyed, 33% prescribed a lower dose occasionally or frequently because they were concerned about being investigated by a regulatory agency.<sup>15</sup> This means that many doctors in New York are not prescribing opioid drugs either when clinically indicated or in the right dose—to the detriment of their patients, many of whom suffer unnecessarily as a result. It would appear that this constitutes malpractice. It certainly is not standard of care,<sup>16</sup> nor is it patient-centered medicine, which focuses medical attention on the patient’s—not the doctor’s—needs. It clearly is a denial of health justice.

### III. PALLIATIVE CARE BEGINNING TO COME OF AGE

According to the Center to Advance Palliative Care:

Palliative care is specialized medical care for people with serious illnesses. This type of care is focused on providing patients with relief from the symptoms, pain and stress of a serious illness—whatever the diagnosis. The goal is to improve quality of life for both the patient and family.

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11. *Id.* at 4-11.

12. Lina Mezie et al., *Pain Education in North American Medical Schools*, 12 J. PAIN 1199 (2011).

13. INST. OF MED. OF THE NAT’L ACADS., *supra* note 8, at 3-25.

14. *See id.* at 3-26.

15. Med. Soc’y of the State of N.Y., *Pain Management Survey*, 60 NEWS N.Y. 8-9 (2005).

16. “Standard of care” refers to the treatment process that a clinician should follow for patients in pain or who have other symptoms given their clinical circumstances.

Palliative care is provided by a team of doctors, nurses, and other specialists who work with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.<sup>17</sup>

Palliative care is for people suffering from any serious and chronic illness, such as cancer, heart disease, pulmonary disease (COPD), kidney failure, Alzheimer's disease, HIV/AIDS, and amyotrophic lateral sclerosis (ALS). It is provided to relieve the symptoms of these diseases, such as pain, shortness of breath, fatigue, constipation, nausea, loss of appetite, and difficulty sleeping. The goal of palliative care is to relieve suffering and provide the best possible quality of life for both the patient and his or her family.<sup>18</sup>

Unfortunately, a survey commissioned in 2011 by the Center to Advance Palliative Care found that there is a lack of knowledge about palliative care. The survey revealed that 70% of the public was "not at all knowledgeable" about palliative care.<sup>19</sup> However, once informed, about 95% agreed that it was important for patients with serious illnesses, as well as their families, to be educated about palliative care. In addition, 92% said they would likely consider palliative care for a loved one if he or she had a serious illness, and 92% also said it is important that palliative care services be made available at all hospitals for patients with serious illnesses and their families.<sup>20</sup> In addition, the survey found that, despite the fact that palliative care can be provided at any time during the course of a disease or illness, "[p]hysicians tend to either equate palliative care with 'hospice' or 'end-of-life' care, and they are very resistant to believing otherwise."<sup>21</sup> This is one of many indicators that physicians have not been well trained in palliative and end-of-life care.<sup>22</sup>

Fortunately, palliative care, including pain care, is increasingly being provided to patients who might benefit, although not nearly extensively enough. Many hospitals still do not have palliative care programs. So while there has been a significant increase in palliative care programs in the past decade, as of 2008, about 20% of hospitals with three hundred beds or more and 60% of hospitals with fifty to seventy-

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17. *Defining Palliative Care*, CTR. TO ADVANCE PALLIATIVE CARE, <http://www.capc.org/building-a-hospital-based-palliative-care-program/case/definingpc> (last visited Dec. 27, 2013).

18. *See id.*

19. CTR. TO ADVANCE PALLIATIVE CARE, 2011 PUBLIC OPINION RESEARCH ON PALLIATIVE CARE 3 (2011), available at <http://www.capc.org/tools-for-palliative-care-programs/marketing/public-opinion-research/2011-public-opinion-research-on-palliative-care.pdf>.

20. *Id.* at 13.

21. *Id.* at 4.

22. According to the Center to Advance Palliative Care, "A major barrier facing the expansion of palliative care services is the lack of palliative medicine physicians. Where there is approximately one cardiologist for every 71 persons experiencing a heart attack and one oncologist for every 141 newly diagnosed cancer patients, there is only one palliative medicine physician for every 1,200 persons living with a serious or life-threatening illness." *A State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals: Recommendations for Action*, CTR. TO ADVANCE PALLIATIVE CARE (2011), <http://www.capc.org/reportcard/recommendations>.

## HEALTH JUSTICE DENIED OR DELAYED AT THE END OF LIFE

four beds were still without palliative care programs.<sup>23</sup> Too many people who would benefit from palliative care are not receiving it and are getting substandard care—a denial of health justice.

### IV. THE NEED FOR PALLIATIVE CARE LAWS TO PROTECT PATIENTS

There was an urgent need in New York for laws ensuring that health care practitioners provided, and patients received, the information and counseling needed to make informed decisions about their treatment and care to reduce the number of patients dying badly. Many physicians have historically been unwilling or unable to have discussions with their dying patients about their diagnosis, prognosis, and treatment options, or those discussions have been inadequate or untimely, in each case to the detriment of their patients. A study involving 332 advanced-stage cancer patients who were followed from the time they were enrolled until they died (an average of 4.4 months) found that only 123 had end-of-life discussions with their physicians.<sup>24</sup>

Yet the vast majority of dying patients want to know their diagnosis and prognosis. In one study of 214 persons aged sixty and older (with a limited life expectancy secondary to cancer, congestive heart failure, or chronic obstructive pulmonary disease), 83% of those believing they had one year or less to live wanted to discuss their prognosis.<sup>25</sup> In another survey, it was found that 95% of patients wanted their oncologist to be honest about their expected survival.<sup>26</sup>

The lack of timely physician-patient communication—or any physician-patient communication—regarding hospice is evident. Hospices provide high-quality end-of-life care with well-trained interdisciplinary teams, similar to palliative care teams. Since hospices provide significant benefits to patients and their families, discussions about hospice should take place and referrals for most patients should be made soon after a terminal diagnosis. However, hospice referrals have usually been made close to death or not at all, even though patients are eligible when a doctor determines that it is likely the patient will die within six months. New York State has had a poor record regarding hospice utilization. The state has one of the lowest rates in the country of patients dying in hospice: about 26% compared to the national average of 41%.<sup>27</sup> And it was reported that 33% of patients were enrolled in hospice for only

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23. See Roxanne Nelson, *Palliative Care Programs Continue to Increase in American Hospitals*, MEDSCAPE (Apr. 20, 2010), <http://www.medscape.com/viewarticle/720534>.

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).

25. Terri R. Fried et al., *Prognosis Communication in Serious Illness: Perceptions of Older Patients, Caregivers, and Clinicians*, 51 J. AM. GERIATRICS SOC'Y 1398, 1399–1402 (2003).

26. A. Bhatnagar et al., *What Do Patients Want from Their Radiation Oncologist? Final Results from a Prospective Randomized Trial*, 75 INT'L RADIATION ONCOLOGY BIOLOGY PHYSICS 186 (2009) (studying patients with three different forms of cancer).

27. *Articles Examine Why Hospice Is Still an "Uncommon Option" in Mohawk Valley (New York State)*, 16 HOSPICE NEWS NETWORK 1 (Sept. 11, 2012), available at <http://www.tnhospice.org/assets/9-11-12.pdf>.

seven days or less, and 32% were enrolled for only eight to thirty-one days before death.<sup>28</sup>

There are significant benefits for patients when end-of-life discussions between physicians and their dying patients occur. Quality of life is improved, decisions are made to pursue less aggressive interventions, patients are more likely to receive end-of-life care consistent with their wishes, and hospice referrals occur earlier.<sup>29</sup> According to one study, when end-of-life discussions took place, patients were “more likely to accept that their illness was terminal (52.9% vs. 28.7%), preferred medical treatment focused on relieving pain and discomfort over life-extending therapies (85.4% vs. 70.0%), and far more completed a do-not-resuscitate order (63.0% vs. 28.5%).”<sup>30</sup> These patients were less likely to be on mechanical ventilators, to be resuscitated, or to be admitted to the intensive care unit. They were also “more likely to be enrolled in outpatient hospice for more than a week (65.6% vs. 44.5%).”<sup>31</sup> Those patients who had aggressive medical interventions had a worse quality of life in their final week, and that quality decreased as the number of aggressive therapies increased. In contrast, those patients who were enrolled in hospice for at least a week had a better quality of life that improved the longer they were in hospice care.<sup>32</sup> Patients with terminal lung cancer who began receiving palliative care immediately upon diagnosis not only had improved moods, were more mobile, and experienced less pain as the end neared, but they also lived nearly three months longer.<sup>33</sup>

End-of-life discussions often produce dramatic positive results. Health justice demands that they take place for dying patients who want to have them. It is the responsibility of health care practitioners to initiate these discussions, as they are now required to do in New York and as both best practice and standard of care dictate. Health justice is improved and expanded when these discussions take place.

Not surprisingly, there are cost savings when end-of-life discussions occur. Patients with advanced-stage cancer who reported having end-of-life conversations with physicians (only 31% of the patients had such discussions) had significantly lower health care costs in their final week of life.<sup>34</sup> And higher costs are associated with worse quality of death. Patients who had end-of-life discussions with their physicians were more likely to receive outpatient hospice care and be referred to hospice earlier.

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28. 2008 *Hospice Utilization and Cost Data*, N.Y. STATE DEP'T OF HEALTH (Nov. 22, 2010), [http://www.nyhealth.gov/statistics/facilities/hospice/utilization\\_and\\_cost/2008/](http://www.nyhealth.gov/statistics/facilities/hospice/utilization_and_cost/2008/).

29. See Wright et al., *supra* note 24; see also Jennifer W. Mack et al., *End-of-Life Discussions, Goal Attainment, and Distress at the End of Life: Predictors and Outcomes of Receipt of Care Consistent with Preferences*, 28 J. CLINICAL ONCOLOGY 1203, 1207–08 (2010).

30. Wright et al., *supra* note 24, at 1668.

31. *Id.*

32. See *id.*

33. See Jennifer S. Temel et al., *Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer*, 363 NEW ENG. J. MED. 733, 739–40 (2010).

34. Baohui Zhang et al., *Health Care Costs in the Last Week of Life: Associations with End-of-Life Conversations*, 169 ARCHIVE INTERNAL MED. 480, 482 (2009).



## V. NEW YORK LAWS REGARDING PALLIATIVE CARE

New York has wisely enacted laws, unique to the state, to begin to address the problems of inadequate pain and other symptom control, the lack of information provided to patients about palliative care and end-of-life options, and the failure to provide timely palliative care, if at all. New York law gives patients a clearly defined right to receive information and counseling on palliative care and to receive palliative care. The Palliative Care Information Act<sup>35</sup> and Palliative Care Access Act,<sup>36</sup> both effective in 2011, are critically important laws. They should have the effect of improving and expanding health justice.

### A. Palliative Care Information Act

When a determination is made that a patient has a terminal illness or condition and death can be reasonably expected within six months, whether or not treatment is provided, the Palliative Care Information Act (PCIA) becomes operative. The key provisions of the law state:

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, including but not limited to: the range of options appropriate to the patient; the prognosis, risks and benefits of the various options; and the patient's legal rights to comprehensive pain and symptom management at the end of life, and
- (b) information regarding other appropriate treatment options should the patient wish to initiate or continue treatment.<sup>37</sup>

"Palliative care" is defined in the law as "health care treatment, including interdisciplinary end-of-life care, and consultation with patients and family members, to prevent or relieve pain and suffering and to enhance the patient's quality of life, including hospice care."<sup>38</sup> The obligation to provide the information and counseling can be fulfilled by the attending physician, a nurse practitioner, or by referring or transferring the patient to another appropriate health care practitioner. If the attending health care practitioner is unwilling to provide information and counseling, the patient *must* be referred to another physician or to a nurse practitioner.<sup>39</sup>

The information can be provided verbally or in writing,<sup>40</sup> although best practice would seem to always require verbal discussions—even if supplemented by

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

36. *Id.* § 2997-d.

37. *Id.* § 2997-c(2)(a)–(b) (emphasis added).

38. *Id.* § 2997-c(1)(c).

39. *See id.* § 2997-c(2)(b), (3).

40. *See id.* § 2997-c(2)(b).

documentation. Of course the patient may decline the offer to receive the information and counseling. If an offer is declined, the practitioner should renew the offer, as appropriate, when the patient's condition changes and different treatment options may be available. If the patient lacks the capacity to understand and make informed choices about palliative care, the information and counseling must be offered to those in authority; that is, a health care agent or surrogate who is authorized to make decisions for the patient.<sup>41</sup>

Compliance with the PCIA requires timely discussions about, and referrals to, hospice. This is critically important given the low rate of hospice use in New York. Virtually all terminally ill patients benefit from hospice and, as a result of the PCIA, significantly more patients should benefit from hospice care at their deaths.

There are two options which should be offered under the PCIA to patients<sup>42</sup> as a last resort when other options cannot sufficiently relieve suffering: (1) voluntarily stopping eating and drinking (VSED) and (2) palliative sedation. Both relieve suffering, but death nevertheless results, as it generally does when life-sustaining treatments such as a feeding tube or a respirator are withdrawn. However, without advocacy by patients and loved ones, these options probably will not be offered, resulting in a denial of health justice.

VSED requires the patient to stop all fluid intake and will hasten death, generally within ten to fourteen days. VSED appears to be legal in every state<sup>43</sup> and is generally a peaceful, dignified way of dying.<sup>44</sup> Palliative sedation is the other option. Even when skilled palliative care is provided, in some cases symptoms may not respond to standard interventions. If the suffering of a dying patient cannot be relieved despite all reasonable efforts to do so, doctors and patients should consider palliative sedation and it should be offered as an option in appropriate situations. Palliative sedation is the use of sedative medications to relieve extreme suffering. Usually the patient is sedated to unconsciousness, other life-sustaining treatment is withdrawn, and the patient will usually die within two weeks. Palliative sedation, while still underutilized, is now widely accepted by groups such as the American Medical Association<sup>45</sup> and the National Hospice and Palliative Care Organization.<sup>46</sup> As VSED and palliative sedation are offered more often to appropriate dying patients, health justice will increase.

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41. *See id.*

42. While no specific options are mentioned in the PCIA other than hospice, in my view, it is essential that the options of VSED and palliative sedation should be offered when other options, including the expert care given by hospice, are insufficient to relieve suffering.

43. *See* Thaddeus M. Pope & Lindsey E. Anderson, *Voluntarily Stopping Eating and Drinking: A Legal Treatment Option at the End of Life*, 17 WIDENER L. REV. 363, 366, 401 (2011).

44. *See* Linda Ganzini et al., *Nurses' Experiences with Hospice Patients Who Refuse Food and Fluids to Hasten Death*, 349 NEW ENG. J. MED. 359, 363 (2003).

45. *See Opinion 2.20—Sedation to Unconsciousness in End-of-Life Care*, AM. MED. ASS'N (Nov. 2008), <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion2201.page>.

46. *See* Timothy W. Kirk & Margaret M. Mahon, *National Hospice and Palliative Care Association (NHPCO) Position Statement and Commentary on the Use of Palliative Sedation in Imminently Dying Terminally Ill Patients*, 39 J. PAIN & SYMPTOM MGMT. 914, 915–16 (2010).

## HEALTH JUSTICE DENIED OR DELAYED AT THE END OF LIFE

### *B. The Palliative Care Access Act*

The Palliative Care Access Act (PCAA)<sup>47</sup> has a much wider application than the PCIA. The PCAA requires hospitals, nursing homes, home care agencies, special needs assisted living residences, and enhanced assisted living residences to establish policies and procedures to provide information about options for palliative care for patients with advanced life limiting conditions. This targets a population likely to benefit from palliative care. Under the PCAA, the identified health care providing organizations must also facilitate access to appropriate palliative care consultation and services, including associated pain management consultation and services, and provide referrals consistent with patient or resident needs and preferences. When a patient lacks the capacity to make medical decisions, the information and counseling must be provided to persons legally authorized to make medical decisions on behalf of the patient.

In a letter to CEOs and health care administrators regarding the PCAA, the New York State Department of Health made the Act's purpose clear:

Like the PCIA, the PCAA is intended to ensure that patients are fully informed of the options available to them when they are faced with a serious illness or condition, so that they are empowered to make choices consistent with their goals for care, wishes and beliefs, and to optimize their quality of life. The law is not intended to limit the options available to patients. Nor is it intended to discourage conversations about palliative care with patients who have distressing symptoms and serious conditions, but do not technically fall within the law's requirements. Patients and providers should recognize that palliative care and disease-modifying therapies are not mutually exclusive. Patients may opt to pursue palliative care while also pursuing aggressive treatment. Palliative care may be provided together with life-prolonging or curative care or as the main focus of care.<sup>48</sup>

### *C. The Role of Professionals in Ensuring Compliance and Tools for Implementation*

It is important for attorneys as well as health care professionals to know about the PCIA and the PCAA. It is evident that the vast majority of health care professionals have not heard of these laws and that there is non-compliance with them to a large extent.<sup>49</sup> Attorneys who know their clients are or may be terminally ill, or may be suffering from an advanced life limiting illness, should be informed of these laws so they can advocate for compliance and for health justice on their client's behalf.

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47. N.Y. PUB. HEALTH LAW § 2997-d (McKinney 2011).

48. Letter from Richard M. Cook, Deputy Comm'r Offices of Health Sys. Mgmt., to CEO/Administrator (Dec. 14, 2011) (on file with N.Y. State Dep't of Health), *available at* [http://www.health.ny.gov/professionals/hospital\\_administrator/letters/2011/2011-12-14\\_pcaa\\_builds\\_on\\_pcia.htm](http://www.health.ny.gov/professionals/hospital_administrator/letters/2011/2011-12-14_pcaa_builds_on_pcia.htm).

49. This observation is based on numerous discussions with, and reports from, health care professionals—including doctors, nurses, and social workers—as well as from lectures I have given to this audience.

Medical Orders for Life-Sustaining Treatment (MOLST),<sup>50</sup> available for use in New York since 2008, is an excellent document which can be used as a tool to have discussions with terminally ill patients, those patients who might die within a year, or those who are in a nursing home. The form constitutes actionable medical orders based on the patient's goals and preferences. A MOLST may be used either to limit medical interventions or to clarify a request for all medically indicated interventions. It is completed by the patient (or the health care agent or surrogate) and the doctor. The MOLST documents the patient's wishes regarding life-sustaining treatment, such as cardiopulmonary resuscitation (in this respect, it is used in place of a traditional do-not-resuscitate order), intubation, mechanical ventilation, feeding tubes, and antibiotics. The MOLST effectively turns the patient's decisions into medical orders that travel with the patient from home to hospital and to any other medical setting. It can include directions about other types of interventions that a patient may or may not want and, in some ways, is similar to a living will. A MOLST is sometimes considered an advance directive, but it has the distinct advantage of constituting medical orders.

In states where a virtually identical form has been used (usually called Physician Orders for Life-Sustaining Treatment (POLST)), there is evidence that patients' wishes are more likely to be honored, particularly regarding resuscitation. A consistency rate of 98% was found at one nursing home between the treatment provided and patients' POLST resuscitation orders. There was also a 94% consistency rate for all orders.<sup>51</sup>

MOLST has been used extensively with great success in upstate New York.<sup>52</sup> Unfortunately, despite the value of the MOLST form, it is still not widely used in hospitals or nursing homes in downstate New York, although that is beginning to change. Attorneys are urged to suggest that their clients, as appropriate based on their individual situations, ask their physicians to complete the MOLST form.

## VI. PROPOSED LEGISLATION

Slow improvements in the provision of pain, palliative, and end-of-life care are not enough when too many people are suffering needlessly and substantial

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50. See generally COMPASSION AND SUPPORT AT THE END OF LIFE, <http://www.compassionandsupport.org> (last visited Dec. 27, 2013) (providing information about MOLST in New York State); see also CHARLES P. SABATINO & NAOMI KARP, IMPROVING ADVANCED ILLNESS CARE: THE EVOLUTION OF STATE POLST PROGRAMS (2011), available at <http://assets.aarp.org/rgcenter/ppi/cons-prot/POLST-Report-04-11.pdf> (providing information about the history of the POLST program).

51. Susan Hickman et al., *The Consistency Between Treatments Provided to Nursing Facility Residents and Orders on the Physicians Orders for Life-Sustaining Treatment Form*, 59 J. AM. GERIATRIC Soc'y 2091, 2094 (2011).

52. See E-mail from Timothy Quill, Dir. of the Ctr. for Ethics, Humanities and Palliative Care and a board-certified palliative care consultant at the Univ. of Rochester Medical Ctr., to author ("We have been using the MOLST for years, and it works very easily and efficiently. Our palliative care group has loads of experience with it—we see about 800–900 inpatient consults per year about half of whom die in the index hospitalization and about 200–400 outpatient consults—I and we are very familiar and comfortable with the MOLST, and I have no reservations about it.").

## HEALTH JUSTICE DENIED OR DELAYED AT THE END OF LIFE

improvements can be made quickly. Remedial legislation is necessary as one way to ensure and accelerate essential, positive changes. The enactment of five bills, three of which have previously been introduced in New York, would quicken necessary improvements.

One bill that would address many of the problems discussed in this article would require periodic continuing medical education for health care professionals on the subjects of pain, palliative medicine, clinical communication skills, patient and family perspectives on end-of-life care, advance care planning, and ethics and the law.<sup>53</sup> Successful course completion should result in: health care practitioners who are better informed about health care proxies, the PCIA, the PCAA, and MOLST, and who have an increased ability to have meaningful discussions with dying patients and their families; better compliance with the PCIA and PCAA; and positive changes in clinical practice.<sup>54</sup>

A second bill that should be enacted would protect health care practitioners from discipline and criminal liability under New York law. This bill would protect doctors who are prescribing, dispensing, or administering pain-relieving medications or other treatments when practicing within the lawful scope of their practice and in accordance with the reasonable standard of care of the profession.<sup>55</sup>

A third bill may be introduced that would prohibit health care providers from recovering any fees for services rendered in contravention of a patient's expressed wishes.<sup>56</sup> The provision of such unwanted treatment or care is unnecessary and should not be compensated.

A fourth bill would amend existing law and require institutions that do not honor the wishes of patients,<sup>57</sup> particularly regarding life-sustaining treatments, to inform patients, health care agents, or surrogates, of the institution's policies prior to admission, except in the case of emergencies.<sup>58</sup>

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53. See A. 01124, 2013 Assemb. (N.Y. 2013) (passed Assembly Mar. 14, 2013); see also S. 2947, 2013 Senate (N.Y. 2013) (passed Health Comm., June 4, 2003, not voted on by full Senate).

54. See generally L. Leong et al., *Evaluating the Impact of Pain Management (PM) Education on Physician Practice Patterns—A Continuing Medical Education (CME) Outcomes Study*, 25 J. CANC. EDUC. 224, 226–27 (2010). Four months after CME training, researchers in California found that 90% of respondents agreed with the statement “I will change/have changed my practice.” *Id.* at 226.

55. See A. 05345, 2013 Assemb. (N.Y. 2013) (passed Assembly June 19, 2013 and referred to S. Rules Comm.).

56. This is based on discussions that I have had with a legislator.

57. There are situations in which the wishes of a patient, or health care agent, or surrogate are disregarded and there is no remedy. This is a denial of health justice that this bill would partially remedy. See, e.g., *Cronin v. Jamaica Hosp. Med. Ctr.*, 875 N.Y.S. 2d. 222, 223 (2d Dep't 2009) (holding that no cause of action exists for “wrongful living” when the hospital twice resuscitated the patient in violation of two do-not-resuscitate orders).

58. See A. 00721, 2013 Assemb. (N.Y. 2013); see also S. 5638, 2013 Senate (N.Y. 2013) (proposing an amendment to the public health law requiring pre-admission notification of policies authorizing the refusal to follow directives in health care proxies that are contrary to a hospital's operating principles).

Finally, a fifth bill may be introduced that would amend the New York Patients' Bill of Rights to require that health care providers offer information about the Palliative Care Information Act and Palliative Care Access Act.<sup>59</sup>

## VII. CONCLUSION

The denial of health justice, especially at the end of life, is far too prevalent, and unnecessary suffering often results. As stated by a highly respected palliative care physician, Ira Byock, the former Director of Palliative Medicine at Dartmouth-Hitchcock Medical Center in New Hampshire, "I passionately believe we have a crisis surrounding the way we care for people in their last phase of life in America."<sup>60</sup> He is right. Improvements are being made, but not nearly as quickly as needed. Much more must be done in order to ensure that people die as well as possible, that their health care wishes are respected, and that they receive health justice at the end of their lives.

Attorneys who work with their clients' health care professionals can play an important role. They can help ensure that existing laws are followed so patients and their families receive the necessary information to make informed decisions about treatment and care. Attorneys can ensure that health care proxies are completed, and that when patients have decisionmaking capacity, they communicate their wishes to loved ones and health care professionals. This will help make certain that desired treatment is provided, unwanted and harmful treatment is not provided, and the expressed wishes of patients or directions of their health care agents or surrogates are respected. Attorneys should think about possible remedial legislation and work to facilitate such legislation. There are many opportunities for involvement.

Health justice at the end of life and the relief of suffering should, and I hope will, become a priority of the health care profession in the near future. It should also be a priority and an important aspect of the work of all attorneys, especially—but not only—for those who practice in the elder or health law fields.

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59. This is based on discussions that I have had with a legislator.

60. Kristine Crane, *Palliative Care Expert: We Are at a Crossroads in End-of-Life Care*, GAINSVILLE SUN (Dec. 6, 2012), <http://www.gainesville.com/article/20121206/ARTICLES/121209755/1109/sports?p=1&tc=pg>.