



1-1-2012

# Palliative Care and Hospice: Opportunities to Improve Care for the Sickest Patients

Kathleen Tschantz Unroe

Diane E. Meier

Follow this and additional works at: <http://scholarship.law.nd.edu/ndjlepp>

### Recommended Citation

Kathleen T. Unroe & D. E. Meier, *Palliative Care and Hospice: Opportunities to Improve Care for the Sickest Patients*, 25 NOTRE DAME J.L. ETHICS & PUB. POL'Y 413 (2012).

Available at: <http://scholarship.law.nd.edu/ndjlepp/vol25/iss2/10>

This Essay is brought to you for free and open access by the Notre Dame Journal of Law, Ethics & Public Policy at NDLScholarship. It has been accepted for inclusion in Notre Dame Journal of Law, Ethics & Public Policy by an authorized administrator of NDLScholarship. For more information, please contact [lawdr@nd.edu](mailto:lawdr@nd.edu).

# PALLIATIVE CARE AND HOSPICE: OPPORTUNITIES TO IMPROVE CARE FOR THE SICKEST PATIENTS

DR. KATHLEEN TSCHANTZ UNROE\* & DR. DIANE E. MEIER†

## I. CONTEXT

Over half of the health care costs in the United States are accounted for by the 5–10% of the population who are chronically or seriously ill.<sup>1</sup> Medicare is the federal insurance program that covers persons over age sixty-five as well as some persons with disabilities. About half of Medicare beneficiaries have both chronic medical conditions combined with functional limitations such as inability to do housework, difficulty walking, or needing assistance with tasks such as bathing.<sup>2</sup> Many of these patients incur high costs to the program.<sup>3</sup> Medicare spends over \$44,220 per person per year for the sickest 10% of beneficiaries.<sup>4</sup>

Unfortunately, despite the enormous use of resources, many patients and their families are frustrated by their health care experiences and receive poor quality of care. Research studies have shown that patients with serious illnesses often have untreated symptoms, unmet personal care needs, and low satisfaction. Family members of these patients often report high caregiver burden and low satisfaction as well.<sup>5</sup> A 2008 survey of

---

\* MD; MHA; Duke University Medical Center and Durham VA Geriatric Research, Education, and Clinical Center; Geriatric Medicine Fellow.

† MD; Director, Center to Advance Palliative Care; Director, Hertzberg Palliative Care Institute, Mount Sinai School of Medicine.

1. THE HENRY J. KAISER FAMILY FOUND., HEALTH CARE COSTS: A PRIMER: KEY INFORMATION ON HEALTH CARE COSTS AND THEIR IMPACT 5 (2009), [http://www.kff.org/insurance/upload/7670\\_02.pdf](http://www.kff.org/insurance/upload/7670_02.pdf).

2. OFFICE OF THE ASSISTANT SEC'Y FOR PLANNING & EVALUATION, DEP'T OF HEALTH & HUMAN SERVS., INDIVIDUALS LIVING IN THE COMMUNITY WITH CHRONIC CONDITIONS AND FUNCTIONAL LIMITATIONS: A CLOSER LOOK 2, 24 (2010) (describing, in the "Data and Definitions" section, examples of functional limitations and stating in the "Conclusion" section that "almost half of older adults had chronic conditions and functional limitations and accounted for over two-thirds of health care expenditures for the group").

3. *Id.* at 24.

4. THE HENRY J. KAISER FAMILY FOUND., MEDICARE FACT SHEET: MEDICARE SPENDING AND FINANCING 1 fig.4 (2008), [http://www.kff.org/medicare/upload/7305\\_03.pdf](http://www.kff.org/medicare/upload/7305_03.pdf) (detailing the average per capita Medicare spending).

5. See INST. OF MED., DIV. OF HEALTH CARE SERVS., APPROACHING DEATH: IMPROVING CARE AT THE END OF LIFE 18 (Marilyn J. Field & Christine K. Cassel

chronically ill adults in Australia, Canada, France, the Netherlands, New Zealand, the United Kingdom and the United States found that U.S. patients reported that they are more likely to forgo needed care because of costs (54%), have problems with care coordination (34%), or experience some type of medical error (34%).<sup>6</sup>

The cost and quality concerns that are central to debates about health care insurance and delivery system reform are especially salient when considering persons with serious illnesses. Palliative care and hospice services are vital to addressing the needs of this population and have the potential to provide higher quality intensive care while using fewer resources.

Palliative care and hospice are able to meet the needs of this high cost population through a focus on symptom management, coordination among providers, and improved transitions of care, such as when a patient is discharged home from the hospital. Caregiver education and support is an important component as well. Working with patients on advance care planning based on their own preferences and values helps avoid unnecessary or unwanted medical interventions.

Don Berwick, founding Director of the Institute for Healthcare Improvement (IHI) and now Administrator of the Center for Medicare and Medicaid Services (CMS) at the U.S. Department of Health and Human Services, describes his goals for innovations in health care design as needing to meet the “triple aim”: improving the patient’s individual experience of care; improving the health of [defined] populations; and reducing the per capita costs of care.”<sup>7</sup> To achieve the triple aim, he argues that a population needs to be specified, policy constraints must be recognized and overcome, and effective integration across the spectrum of health services is necessary.<sup>8</sup> Palliative care and hospice services support the objectives of the triple aim by targeting a specific population and offering services that are tailored to a patient’s and family’s needs and goals, often reducing unwanted

---

eds., 1997); Joan M. Teno et al., *Family Perspectives on End-of-Life Care at the Last Place of Care*, 291 JAMA 88, 92 (2004); Kenneth E. Thorpe & David H. Howard, *The Rise in Spending Among Medicare Beneficiaries: The Role of Chronic Disease Prevalence and Changes in Treatment Intensity*, 25 HEALTH AFF. WEB EXCLUSIVE W378, W383–85 (2006).

6. Cathy Schoen et al., *In Chronic Condition: Experiences of Patients with Complex Health Care Needs, in Eight Countries, 2008*, 28 HEALTH AFF. WEB EXCLUSIVE W1, W5–10 (2009).

7. Donald M. Berwick et al., *The Triple Aim: Care, Health, and Cost*, 27 HEALTH AFF. 759, 760 (2008).

8. *Id.* at 762.

and avoidable medical interventions. The ability of palliative care and hospice to reach the population appropriate for such services can be augmented by improved policies and health system integration.

## II. HOSPICE VS. NONHOSPICE PALLIATIVE CARE

Patients, providers, and the general public often confuse the terms hospice “and” nonhospice palliative care. Palliative care is focused on achieving the best quality of life possible and relieving patients’ suffering. Palliative care involves assessment and treatment of symptoms such as pain, nausea, and shortness of breath; support for matching patient goals to treatments; mobilization of community resources to support people in their homes; collaborative care across settings; and practical support for patients and caregivers. Palliative care can be provided within the context of hospice services or outside of them. Nonhospice palliative care is appropriate for persons who are living with serious, complex, and life threatening illnesses and may be offered simultaneously with life prolonging and curative therapies.

Hospice, as defined by the Medicare Hospice Benefit, is restricted by statute to patients who have a terminal prognosis of six months or less<sup>9</sup> and agree to forego curative or life-prolonging treatments.<sup>10</sup> The hospice benefit was designed for clearly dying patients to provide team-based palliative care, usually at home.<sup>11</sup> Hospice is appropriate when curative treatments are no longer beneficial, when the burdens of treatments outweigh benefits, or when patients enter the last weeks to months of life.<sup>12</sup>

Interdisciplinary teams that provide hospice and nonhospice palliative care are usually composed of physicians, nurses, and social workers as well as professionals from other disciplines such as chaplains, psychologists, and physical therapists. Communication with patients and families is emphasized to establish achievable goals of care and a care plan matched to those goals. The team also works to support patients and families during crises and assists with planning for safe transitions across settings, for example, from the hospital to home.

---

9. NAT’L CONSENSUS PROJECT FOR QUALITY PALLIATIVE CARE, CLINICAL PRACTICE GUIDELINES FOR QUALITY PALLIATIVE CARE 11 (2d ed. 2009).

10. DEP’T OF HEALTH & HUMAN SERVS., CTRS. FOR MEDICARE & MEDICAID SERVS., MEDICARE HOSPICE BENEFITS 4 (2010), <http://www.medicare.gov/publications/pubs/pdf/02154.pdf>.

11. *Id.*

12. R. Sean Morrison & Diane E. Meier, *Clinical Practice: Palliative Care*, 350 NEW ENG. J. MED. 2582, 2587 tbl.2 (2004) (describing a review of the “benefit-to-burden ratio for disease modifying treatments”).

## III. HISTORY OF HOSPICE

In his 1981 book, *The Hour of Our Death*, historian Phillipe Ariès traces changes in Western attitudes towards death and dying from early Christian times to the modern era. He describes our current phase as the “Invisible Death,” where death has been banished as an unacceptable and unendurable truth and where death is believed to be avoidable with enough investment in research.<sup>13</sup> If it is presumed that death can be defeated by science, then when it does occur it theoretically could have been prevented and thus must reflect a failure—of the family to find the right doctor; of the patient to take care of himself; of the doctors or hospitals to know and provide the right treatments; and of society to invest enough in research. Even though over 80% of Americans report religious affiliation,<sup>14</sup> the attitude that death is preventable implies that someone or something under human control must be to blame when it happens.

When death is believed to be avoidable and therefore a failure, it becomes stigmatized and hidden. This stigma of death as failure, the widely held belief that modern medicine can perform miracles in the battle against death, and the multi-year course of the chronic illnesses responsible for 75% of deaths in the United States have fostered an environment where over 70% of deaths in the United States occur in institutions—hospitals and nursing homes.<sup>15</sup> The hospital is believed to have the people and technology needed to keep death at bay. Further, the hospital and the nursing home offer respite for families from the difficult, often many years long, work of caring for a seriously ill person. The modern ritual of death involves several prolonged stays in the hospital, often in an intensive care unit. This ritual allows the family to say, “We did everything possible, we got the best care possible” and to keep the exhausting, concrete, and physically and emotionally distressing aspects of illness at a controlled distance.

Reaction against the stigma and the isolation of the dying that accompanied the view of death as somehow optional or pre-

---

13. PHILIPPE ARIÈS, *THE HOUR OF OUR DEATH* 575 (Helen Weaver trans., 1981).

14. *Statistics on Religion in America Report*, PEW FORUM ON RELIGION & PUBLIC LIFE, <http://religions.pewforum.org/reports> (last visited Apr. 20, 2011) (providing statistics on the percentage of the U.S. population that affiliates with certain religious traditions).

15. See Andrea Gruneir et al., *Where People Die: A Multilevel Approach to Understanding Influences on Site of Death in America*, 64 *MED. CARE RES. REV.* 351, 362 tbl.1 (2007).

ventable is the foundation of the hospice and, subsequently, palliative care movements in the United States.

“The term ‘hospice’—from the Latin *hospitium*, the same linguistic root as ‘hospitality’—denotes a place to host, receive, and entertain guests or strangers.”<sup>16</sup> The earliest hospitals and hospices were one entity, based in the church, such as St. Bartholomew’s Hospital in London, which was founded in 1123 for the indigent.<sup>17</sup> In the 18th and 19th centuries, religious orders established hospices to care for the dying in France, Ireland, and England.<sup>18</sup>

Cicely Saunders, the founder of the modern hospice and palliative care movements, was a nurse, social worker, and physician.<sup>19</sup> Her first exposure to hospice care was St. Joseph’s Hospice for the Dying Poor established by the Irish Sisters of Charity in London.<sup>20</sup> She founded St. Christopher’s Hospice in London in 1967, the first modern purpose-built hospice facility.<sup>21</sup> Dame Saunders studied effective pain management and emphasized rigorous scientific methodology in the testing of treatments.<sup>22</sup> She insisted that dying people needed dignity, compassion, and respect.<sup>23</sup> She spoke at Yale University in 1963 on specialized care for the dying and was invited back as a visiting professor by Florence Wald, dean of Yale’s School of Nursing.<sup>24</sup> Wald spent a sabbatical at St. Christopher’s in London and came back to establish the first American hospice, the Connecticut Hospice, in 1974,<sup>25</sup> which stimulated the development of hospices across the country.

In 1978, a task force from the Department of Health, Education, and Welfare reported that

---

16. Diane E. Meier, *The Development, Status, and Future of Palliative Care*, in ROBERT WOOD JOHNSON FOUND., SERIES ON HEALTH POLICY, PALLIATIVE CARE: TRANSFORMING THE CARE OF SERIOUS ILLNESS 3, 16 (Diane E. Meier et al. eds., 2010).

17. See *The History of St. Bartholomew’s Hospital*, BARTS & THE LONDON NHS TRUST, <http://www.bartsandthelondon.nhs.uk/about-us/our-history/history-of-modern-medicine-and-timelines/the-history-of-st-bartholomew-s-hospital/> (last visited Apr. 10, 2011).

18. See *Short History of Hospices*, HOSPICE EDUC. INST., <http://www.hospiceworld.org/history.htm> (last visited Apr. 10, 2011).

19. Caroline Richmond, *Obituaries: Dame Cicely Saunders, Founder of the Modern Hospice Movement*, 331 BRIT. MED. J. 238, 238 (2005).

20. Meier, *supra* note 16, at 16–17.

21. Richmond, *supra* note 19, at 238.

22. *Id.*

23. Meier, *supra* note 16, at 21.

24. *Id.* at 17.

25. *Id.* at 21.

the hospice movement as a concept for the care of the terminally ill and their families is a viable concept and one which holds out a means of providing more humane care for Americans dying of terminal illness while possibly reducing costs. As such, it is the proper subject of federal support.<sup>26</sup>

The Medicare hospice benefit was created in 1982 and eligibility criteria were established by law in 1986 to restrict access in order to control the costs of the program.<sup>27</sup> These criteria require patients to give up insurance coverage for life-prolonging treatments related to their terminal illness and also require two physicians to certify that the patient will likely die in six months.<sup>28</sup> For the public, as well as health professionals, hospice became associated with “giving up” in part because of these statutory requirements.<sup>29</sup>

Despite restrictions to the benefit, growth of hospice has been dramatic over the past few decades. In 2009, an estimated 1.56 million patients received hospice services, accounting for about 40% of all deaths in the United States.<sup>30</sup> The median length of stay has remained fairly steady over the past four years at around 20–21 days, and about one-third of patients live for less than one week after admission to hospice.<sup>31</sup> Referrals to hospice tend to occur late in the dying process.<sup>32</sup>

#### IV. OUTCOMES

Multiple studies of palliative care and hospice programs have shown that they improve physical<sup>33</sup> and psychological<sup>34</sup>

26. *Id.* at 18.

27. *Id.*

28. Medicare Hospice Benefit, 42 C.F.R. §§ 418.20, 418.22(b) (2002).

29. Meier, *supra* note 16, at 18; *see also* Elisabeth Kübler-Ross, *Hope*, reprinted in PALLIATIVE CARE: TRANSFORMING THE CARE OF SERIOUS ILLNESS, *supra* note 16, at 111, 114.

30. NAT'L HOSPICE & PALLIATIVE CARE ORG., NHPCO Facts and Figures: Hospice Care in America 4 (2010), [http://www.nhpco.org/files/public/Statistics\\_Research/Hospice\\_Facts\\_Figures\\_Oct-2010.pdf](http://www.nhpco.org/files/public/Statistics_Research/Hospice_Facts_Figures_Oct-2010.pdf).

31. *Id.* at 5 (stating that median length of service in 2009 was 21.1 days and the median in 2008 was 21.3 days); NAT'L HOSPICE & PALLIATIVE CARE ORG., NHPCO Facts and Figures: Hospice Care in America 5 (2008), [http://www.mass.gov/Ihqcc/docs/expert\\_panel/2008\\_NHPCO\\_Facts%20and%20Figures.pdf](http://www.mass.gov/Ihqcc/docs/expert_panel/2008_NHPCO_Facts%20and%20Figures.pdf) (stating that the median length of service in 2007 was 20.0 days and the median in 2006 was 20.6 days).

32. Meier, *supra* note 16, at 19; *see* NAT'L HOSPICE & PALLIATIVE CARE ORG., *supra* note 30, at 5.

33. *See* David Casarett et al., *Do Palliative Consultations Improve Patient Outcomes?*, 56 J. AM. GERIATRICS SOC'Y 593, 597 (2008); Irene J. Higginson et al., *Is*

symptoms experienced by patients, impact caregiver well-being,<sup>35</sup> and improve patient,<sup>36</sup> family,<sup>37</sup> and physician satisfaction.<sup>38</sup> Interdisciplinary palliative care and hospice teams reduce medical complications and expensive hospital utilization by identifying and treating distressing patient symptoms. In a detailed study of patients at an academic medical center who were referred to an inpatient palliative care consult service, it was found that the consultants made an average of 4.23 recommendations per patient and that 91% of these recommendations were followed by the primary medical team.<sup>39</sup> For 94% of the patients, the consult service led discussions about prognosis and goals of care, and there was a modification of understanding of these issues in 89% of cases.<sup>40</sup> About three-fourths of the consults involved management of symptoms, such as pain and shortness of breath.<sup>41</sup> The researchers note that the clarification of goals of care and assistance of the palliative care consult service in discharge planning enables discharges that are consistent with patient wishes, often leading to care at home and avoidance of unnecessary hospital costs.<sup>42</sup> They further note that the work of the palliative care consultants is time intensive, often requiring multiple visits per patient in order to communicate with everyone involved in the patient's care.<sup>43</sup>

The dedicated discussions held by palliative care and hospice providers about prognosis and patient goals have been

---

*There Evidence That Palliative Care Teams Alter End-of-Life Experiences of Patients and Their Caregivers?*, 25 J. PAIN & SYMPTOM MGMT. 150, 164 (2003).

34. See Jennifer S. Temel et al., *Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer*, 363 NEW ENG. J. MED. 733, 740 (2010).

35. See Higginson et al., *supra* note 33, at 161; 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, 1668–70 (2008).

36. See Temel et al., *supra* note 34, at 740; Wright et al., *supra* note 35, at 1668.

37. See Casarett et al., *supra* note 33, at 597; Gerd Inger Ringdal et al., *Family Satisfaction with End-of-Life Care for Cancer Patients in a Cluster Randomized Trial*, 24 J. PAIN & SYMPTOM MGMT. 53, 61 (2002).

38. See Jill A. Marsteller et al., *Physician Satisfaction with Chronic Care Process: A Cluster-Randomized Trial of Guided Care*, 8 ANNALS FAM. MED. 308, 313–14 (2010).

39. Paolo L. Manfredi et al., *Palliative Care Consultations: How Do They Impact the Care of Hospitalized Patients?*, 20 J. PAIN & SYMPTOM MGMT. 166, 172 (2000).

40. *Id.* at 168.

41. *Id.* at 169–70.

42. See *id.* at 168–70.

43. *Id.* at 171.



shown to reduce costs<sup>44</sup> and increase family satisfaction.<sup>45</sup> Studies that have compared the experiences of patients who died during a hospitalization when an inpatient palliative care team was consulted, versus when they were not, have found that palliative care involvement led to overall lower costs.<sup>46</sup> One study found that most of the lower costs were due to reduced use of intensive care unit days.<sup>47</sup> In contrast to many assumptions that palliative care and hospice care may hasten death, recent studies have demonstrated that palliative care and hospice may be associated with *prolongation* of life.<sup>48</sup> An analysis of nearly 4,500 Medicare patients with heart failure or cancer found that survival of patients who received some hospice services was nearly a month longer than patients who did not receive hospice.<sup>49</sup> A recent study randomized patients with advanced lung cancer to receive palliative care along with standard oncology care as compared with patients receiving only standard oncology care. Although the patients receiving palliative care along with best cancer care were less likely to receive aggressive care, they had an improved survival benefit of 2.7 months compared to the best cancer care only control group.<sup>50</sup>

---

44. Baohui Zhang et al., *Health Care Costs in the Last Week of Life: Associations with End-of-Life Conversations*, 169 ARCHIVES INTERNAL MED. 480, 482–84 (2009).

45. See Ringdal et al., *supra* note 37, at 61; Wright et al., *supra* note 35, at 1671.

46. Ahmed Elsayem et al., *Palliative Care Inpatient Service in a Comprehensive Cancer Center: Clinical and Financial Outcomes*, 22 J. CLINICAL ONCOLOGY 2008, 2012–13 (2004); R. Sean Morrison et al., *Cost Savings Associated with US Hospital Palliative Care Consultation Programs*, 168 ARCHIVES INTERNAL MED. 1783, 1785 (2008); Joan D. Penrod et al., *Cost and Utilization Outcomes of Patients Receiving Hospital-Based Palliative Care Consultation*, 9 J. PALLIATIVE MED. 855, 857–58 (2006); Thomas J. Smith et al., *A High-Volume Specialist Palliative Care Unit and Team May Reduce In-Hospital End-of-Life Care Costs*, 6 J. PALLIATIVE MED. 699, 703–04 (2003).

47. Penrod et al., *supra* note 46, at 857.

48. See Stephen R. Connor et al., *Comparing Hospice and Nonhospice Patient Survival Among Patients Who Die Within a Three-Year Window*, 33 J. PAIN & SYMPTOM MGMT. 238, 243 (2007); Bruce Pyenson et al., *Medicare Cost in Matched Hospice and Non-Hospice Cohorts*, 28 J. PAIN & SYMPTOM MGMT. 200, 207 (2004); Temel et al., *supra* note 34, at 739. *But see* Marie Bakitas et al., *Effects of a Palliative Care Intervention on Clinical Outcomes in Patients with Advanced Cancer: The Project ENABLE II Randomized Controlled Trial*, 302 JAMA 741, 746–47 (2009) (finding that palliative care did not prolong survival of patients).

49. Connor et al., *supra* note 48, at 242.

50. Temel et al., *supra* note 34, at 739.

## V. ACCESS ISSUES

The growth in the use of hospice services over the last several years has improved access to hospice-palliative care in the terminal stages of illness. In 2000, only 23% of Medicare beneficiaries used hospice services, whereas by 2008 nearly 40% of decedents had hospice care at some point during their illnesses.<sup>51</sup> A recent study of Medicare beneficiaries with heart failure also found increasing rates of hospice usage over time; however, about 37% of hospice patients in that study received services for seven days or less, 19% received it for three days or less, and those percentages did not change from 2000 to 2007.<sup>52</sup> Very short stays reduce the opportunity for patients and their families to receive the full benefit of hospice services and also limit the ability of hospice care to have a positive impact upon the use of other health care resources, i.e., reducing avoidable hospitalization and other intensive services or procedures near the end of life.

### A. Settings of Care

Access to palliative care services other than hospice for patients with serious illnesses has improved as a result of the dramatic increase in the availability of such programs in hospitals. Hospitals are the main site of care for the seriously ill and the site of death for about 50% of adults.<sup>53</sup> As of 2008, nearly 40% of U.S. hospitals with 50 to 74 beds and about 80% of hospitals with more than three hundred beds had palliative care programs.<sup>54</sup> While many hospital-based palliative care programs are developing outpatient programs, the numbers remain small. Increased availability of outpatient palliative care services is an important focus for policy efforts aimed at improving access to palliative care for seriously and chronically ill persons starting at the point of diagnosis.

---

51. MEDICARE PAYMENT ADVISORY COMM'N, REPORT TO THE CONGRESS: MEDICARE PAYMENT POLICY 145, 148 (2010).

52. Kathleen T. Unroe et al., *Resource Use in the Last 6 Months of Life Among Medicare Beneficiaries with Heart Failure, 2000–2007*, 171 ARCHIVES INTERNAL MED. 196 (2010).

53. See Gruneir, *supra* note 15, at 362 tbl.1.

54. CTR. TO ADVANCE PALLIATIVE CARE, ANALYSIS OF U.S. HOSPITAL PALLIATIVE CARE PROGRAMS 1–2 (2010), available at [http://www.capc.org/news-and-events/releases/analysis-of-us-hospital-palliative-care-programs-2010-snapshot.pdf/file\\_view](http://www.capc.org/news-and-events/releases/analysis-of-us-hospital-palliative-care-programs-2010-snapshot.pdf/file_view) (follow “click here to get file” hyperlink); see also AM. HOSP. ASS'N, AHA HOSPITAL STATISTICS 165 (2008); Benjamin Goldsmith et al., *Variability in Access to Hospital Palliative Care in the United States*, 11 J. PALLIATIVE MED. 1094, 1099 (2008).

About 25% of Americans die in nursing homes;<sup>55</sup> this percentage is projected to rise substantially with the aging of the U.S. population and the associated increase in numbers of persons with advanced cognitive impairment. A study of access to palliative care in nursing homes found that while some components of palliative care are delivered in most nursing homes, few facilities have formal palliative care programs.<sup>56</sup> Further, the perception by leaders in nursing homes of the quality of palliative care they deliver often is different from the experience of the residents and their families.<sup>57</sup> Medicare beneficiaries living in nursing homes have increasingly used hospice; in 2005, about 30% of Medicare patients receiving hospice lived in nursing homes.<sup>58</sup> Overall, however, only 6% of nursing home residents annually elect to receive hospice care, and even fewer receive nonhospice palliative care services.<sup>59</sup> Hospice patients in nursing homes are more likely to have dementia or other non-cancer terminal diagnoses associated with long periods of decline and uncertain prognoses.<sup>60</sup> As a result, they are more likely to have longer lengths of stay in hospice before death compared to beneficiaries who do not live in nursing homes.<sup>61</sup> The longer stays and associated higher reimbursement costs for nursing home patients on hospice has prompted scrutiny from policymakers, some of whom question whether longer term palliative care needs of patients with advanced dementia are an appropriate use of the hospice benefit.<sup>62</sup> Others have argued, however, that the hospice benefit provides necessary access to palliative care for nursing home patients that is not otherwise available.

---

55. See Gruneir, *supra* note 15, at 362 tbl.1.

56. CTR. TO ADVANCE PALLIATIVE CARE, *IMPROVING PALLIATIVE CARE IN NURSING HOMES* 3.3 (2008).

57. *Id.*

58. DANIEL R. LEVINSON, DEP'T OF HEALTH & HUMAN SERVS., *MEDICARE HOSPICE CARE FOR BENEFICIARIES IN NURSING FACILITIES: COMPLIANCE WITH MEDICARE COVERAGE REQUIREMENTS 2* (2009), <http://oig.hhs.gov/oei/reports/oei-02-06-00221.pdf>.

59. Diane E. Meier et al., *Raising the Standard: Palliative Care in Nursing Homes*, 29 *HEALTH AFF.* 136, 138 (2010).

60. LEVINSON, *supra* note 58, at 2; David G. Stevenson et al., *Hospice Care in the Nursing Home Setting: A Review of the Literature*, 38 *J. PAIN & SYMPTOM MGMT.* 440, 442 (2009).

61. DANIEL R. LEVINSON, DEP'T OF HEALTH & HUMAN SERVS., *MEDICARE HOSPICE CARE: A COMPARISON OF BENEFICIARIES IN NURSING FACILITIES AND BENEFICIARIES IN OTHER SETTINGS 13* (2007), <http://oig.hhs.gov/oei/reports/oei-02-06-00220.pdf>.

62. MEDICARE PAYMENT ADVISORY COMM'N, *REPORT TO THE CONGRESS: MEDICARE PAYMENT POLICY 367* (2009).

### B. Racial Differences

Use of hospice and palliative care services varies by race; several researchers have documented the lower use of hospice by African American patients compared to white patients.<sup>63</sup> Cultural values cited as reasons for decreased use of hospice services include the view that hospice is in conflict with religious beliefs, as it implies “giving up” on life, and that aggressive life-sustaining treatment is superior care.<sup>64</sup> A lack of awareness of available hospice and palliative care services, a lower likelihood of having health insurance coverage, and a mistrust of the health care system in general have also been cited as barriers to African Americans in choosing hospice care.<sup>65</sup>

### C. Workforce

While the increasing availability of clinical palliative care programs represents forward progress in the field, workforce development lags behind. Multiple national reports have called attention to this issue.<sup>66</sup> The 2001 Institute of Medicine (IOM) report *Improving Palliative Care for Cancer* states that “[m]ost new physicians leave medical school and residency programs with little training or experience in caring for dying patients.”<sup>67</sup> It reports that appropriately trained nurses and social workers are also in short supply.<sup>68</sup> The IOM report makes the following recommendations to improve training in medicine, nursing, and social work: (1) faculty development; (2) education materials and curriculum development; (3) coordination among training programs for the variety of professionals involved in the care of dying patients; (4) guidelines for residency programs and increased palliative and end-of-life content in licensing and certi-

---

63. Karla T. Washington et al., *Barriers to Hospice Use Among African Americans: A Systematic Review*, 33 HEALTH & SOC. WORK 267, 267–68 (2008).

64. *Id.* at 270.

65. *Id.* at 268.

66. See INST. OF MED., *supra* note 5, at 207 (discussing deficiencies in curriculum, educational materials, and clinical experiences for students and residents); INST. OF MED. & NAT’L RESEARCH COUNCIL, *IMPROVING PALLIATIVE CARE FOR CANCER 4* (Kathleen M. Foley & Hellen Gelband eds., 2001) (discussing inadequate training, inadequate standards of care, and lack of accountability in caring for dying patients); Hellen Gelband, *Professional Education in Palliative and End-of-Life Care for Physicians, Nurses, and Social Workers*, in INST. OF MED. & NAT’L RESEARCH COUNCIL, *IMPROVING PALLIATIVE CARE FOR CANCER 277, 277* (Kathleen M. Foley & Hellen Gelband eds., 2001) (asserting nationwide need to train next generation of clinicians to care for dying patients).

67. Gelband, *supra* note 66, at 284.

68. *Id.* at 299, 303–04.

fyng examinations; and (5) improving the research base for palliative care education.<sup>69</sup>

To increase and improve training of palliative medicine specialists, leaders in the field pursued subspecialty status. In 2006, palliative medicine became a subspecialty recognized by the American Board of Internal Medicine, and the first certifying exam was offered in 2008.<sup>70</sup> There are now about seventy certified post-graduate fellowship-training programs in palliative medicine.<sup>71</sup> In 2007 the American Board of Nursing Specialties approved accreditation for a master's-level hospice and palliative care certification program.<sup>72</sup>

Certified nursing assistants (CNAs) provide much of the direct care for seriously ill patients in health care institutions. For nursing home patients, they provide up to 90% of the daily care.<sup>73</sup> CNAs frequently work with residents who are dying. A national survey of CNAs found that nearly 70% reported experiencing the death of a resident at some point during the past week.<sup>74</sup> In smaller focus groups, CNAs stated that they were not prepared to help residents at the end of life. They reported feeling helpless to reduce pain and make residents more comfortable. They also expressed difficulty in dealing with their own grief when residents they cared for died.<sup>75</sup>

#### D. Institutional Capacity

While growth in the use of hospice services and the increase in access to inpatient palliative care services have been dramatic, access in other settings, especially in certain geographic areas and among certain racial/ethnic groups, varies. Smaller (less than 100 beds), for-profit, and Southern hospitals are less likely to have palliative care programs.<sup>76</sup> From 2001 to 2005, hospice

69. *Id.* at 306–08.

70. Meier, *supra* note 16, at 39.

71. *Fellowship Accreditation*, AAHPM, <http://www.aahpm.org/fellowship/default/accreditation.html> (last visited Apr. 20, 2011).

72. Meier, *supra* note 16, at 39.

73. JANE C. SIDWELL ET AL., HPNA POSITION STATEMENT, THE VALUE OF THE NURSING ASSISTANT IN END OF LIFE CARE 1 (2005), [http://www.hpna.org/pdf/PositionStatement\\_ValueOfCNAs.pdf](http://www.hpna.org/pdf/PositionStatement_ValueOfCNAs.pdf).

74. JANET REHNQUIST, DEP'T OF HEALTH & HUMAN SERVS., NURSE AIDE TRAINING 17 (2002), <http://oig.hhs.gov/oei/reports/oei-05-01-00030.pdf>.

75. *Id.*

76. See CTR. TO ADVANCE PALLIATIVE CARE, AMERICA'S CARE OF SERIOUS ILLNESS: A STATE-BY-STATE REPORT CARD ON ACCESS TO PALLIATIVE CARE IN OUR NATION'S HOSPITALS 13–21 (2008), <http://www.capc.org/reportcard/state-by-state-report-card.pdf>; CTR. TO ADVANCE PALLIATIVE CARE, ANALYSIS OF U.S. HOSPITAL PALLIATIVE CARE PROGRAMS: 2010 SNAPSHOT 1–2 (2010), <http://>

care was provided in 10% of deaths in Alaska, in contrast to Arizona where hospice was involved in 50.1% of deaths.<sup>77</sup> Increasing the availability of services for the seriously and terminally ill across settings and regions requires a thorough assessment of institutional capacity. The right leadership, management, and resources must be in place to implement programs. Strengthening the workforce at all levels is needed for successful expansion of hospice and palliative care programs.

## VI. IMPROVING THE EVIDENCE BASE

Many have recognized the need for improved investment in palliative care research. Three IOM reports,<sup>78</sup> two National Institute of Health (NIH) state-of-science conferences,<sup>79</sup> and the research committee of the American Academy of Hospice and Palliative Medicine<sup>80</sup> have discussed this need, specifically for research in the areas of pain and symptom management, communication skills, care coordination, and models of care delivery.

Much palliative care research has been supported solely by private-sector philanthropy. A recent study found that less than one percent of NIH extramural funding between 2003 and 2005 was for palliative care-related research.<sup>81</sup> The August 2010 U.S. Senate Appropriations Committee report for the Departments of Labor, Health and Human Services, and Education called for a comprehensive NIH strategy to address this issue:

*Palliative Care.*—The Committee strongly urges the NIH to develop a trans-Institute strategy for increasing funded research in palliative care for persons living with chronic and advanced illness. Research is needed on: treatment of pain and common non-pain symptoms across all chronic

---

[www.capc.org/news-and-events/releases/analysis-of-us-hospital-palliative-care-programs-2010-snapshot.pdf/file\\_view](http://www.capc.org/news-and-events/releases/analysis-of-us-hospital-palliative-care-programs-2010-snapshot.pdf/file_view).

77. *Percent of Decedents Enrolled in Hospice During the Last Six Months of Life*, THE DARTMOUTH ATLAS OF HEALTH CARE, <http://www.dartmouthatlas.org/data/bar.aspx?ind=16> (last visited Apr. 20, 2011).

78. See INST. OF MED., *supra* note 5; INST. OF MED. & NAT'L RESEARCH COUNCIL, *supra* note 66; INST. OF MED. & NAT'L RESEARCH COUNCIL, WHEN CHILDREN DIE: IMPROVING PALLIATIVE AND END-OF-LIFE CARE FOR CHILDREN AND THEIR FAMILIES (Marilyn J. Field & Richard E. Behrman eds., 2002).

79. See NAT'L INSTS. OF HEALTH, NIH STATE-OF-THE-SCIENCE CONFERENCE STATEMENT ON IMPROVING END-OF-LIFE CARE (2004); NAT'L INSTS. OF HEALTH, NIH STATE-OF-THE-SCIENCE STATEMENT ON SYMPTOM MANAGEMENT IN CANCER: PAIN, DEPRESSION, AND FATIGUE (2002).

80. See AM. ACAD. OF HOSPICE & PALLIATIVE MED., RECOMMENDATIONS FOR HEALTH CARE REFORM (2009).

81. Laura P. Gelfman & R. Sean Morrison, *Research Funding for Palliative Medicine*, 11 J. PALLIATIVE MED. 36, 38 (2008).

disease categories, which should include cancer, heart, renal and liver failure, lung disease, Alzheimer's disease and related dementias; methods to improve communication about goals of care and treatment options between providers, patients, and caregivers; care models that maximize the likelihood that treatment delivered is consistent with patient wishes; and care models that improve coordination, transitions, caregiver support, and strengthen the likelihood of remaining at home.<sup>82</sup>

In addition to advancing the science of the field through rigorous research, the development of appropriate metrics to enhance evaluation of programs is crucial. Currently, information on the quality of palliative care and hospice programs is limited. In contrast to other providers, Medicare has not required hospices to report quality data. This was changed in the Patient Protection and Affordable Care Act of 2010 (PPACA),<sup>83</sup> which now requires the federal government to publish quality measures for hospice by October 1, 2012.<sup>84</sup> Nonhospice palliative care programs also have no publicly reported quality metrics. The certifying body for hospitals, The Joint Commission, has developed a voluntary certificate program for palliative care, but it has not yet been released. Quality measures that are developed for hospice and palliative care must demonstrate a link between structure, process, and relevant patient-centered outcomes in order to be meaningful to patients and providers.

## VII. 2010 AFFORDABLE CARE ACT

During the debate surrounding health care reform in 2009, proposed provisions regarding palliative care were removed from the bill prior to its passage. However, there are some provisions within the PPACA that relate to hospice, including payment reforms and a quality reporting mandate that requires hospice and palliative care quality measure development. There are also "Concurrent Care Demonstration" projects in Medicare, as well as for children in Medicaid and Children's Health Insurance Program, that will allow patients to receive simultaneous hospice services and life-prolonging treatments and will additionally study outcomes for quality of life, patient care, and cost-effectiveness.<sup>85</sup>

---

82. S. REP. NO. 111-243, at 125-26 (2010).

83. Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119 (2010) (to be codified as amended in scattered sections of 25 U.S.C., 26 U.S.C., 29 U.S.C., and 42 U.S.C.).

84. *Id.* § 3004, 124 Stat. at 368.

85. *Id.* § 3140, 124 Stat. at 440.

Delivery and payment reform through models such as medical and health homes, accountable care organizations, and payment bundling provide opportunities for the integration of palliative care and hospice into the healthcare continuum. These models aim to improve quality and control costs for defined populations by focusing on intensive care coordination, early identification of problems to prevent emergency room visits or hospitalizations, and shifting provider incentives from traditional fee-for-service reimbursement to payment based on the quality of care delivered. The skills of palliative care and hospice providers can augment the ability of health care institutions and practice groups to meet these goals.

### VIII. CONCLUSION

Palliative care and hospice services are key to addressing the quality and cost concerns in the U.S. health care system. These services improve care for dying patients, as well as for people living with serious, complex, and life-threatening illnesses, by relieving distressing physical and psychological symptoms, matching patient goals to treatments, supporting caregivers, and providing coordinated and collaborative care. Researchers have also demonstrated the potential for these programs to provide overall cost savings. There is significant work to be done, however, in providing consistent access to high quality hospice and palliative care to all appropriate populations and across settings. This will require changes in policy and regulation, as well as continued provider and patient education and activation.

Public misperceptions about palliative care and hospice must be addressed through education and social marketing. The workforce necessary to meet the needs of this population should be supported by strengthening educational efforts for medicine, nursing, nursing aides, social work, and other disciplines. Furthering the research agenda of the field is a necessary component of increasing access to high quality, evidence-based palliative care. Building on the strength and skills of existing hospice and inpatient palliative care providers will help health care organizations meet the goals of new payment and delivery models included in the PPACA. Improved access to palliative care services in other settings, such as outpatient clinics, office locations, and nursing homes, can be achieved through policies and regulations requiring better integration of palliative care across health systems.

Palliative care and hospice programs continue to transform the care experience of seriously ill patients. Barriers to expan-



sion and improved integration of these services must be addressed in order to fully leverage the potential impact of palliative and hospice care upon cost drivers, and to improve quality of care for high need populations.