

MAKING TOUGH CHOICES

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In this article, Dr. Cantor examines the state of palliative care in the United States. Most Americans have not given much thought to either how they will die or the kinds of services they will need while coping with fatal chronic illnesses. Dr. Cantor first points out trends in death and dying, and then discusses the three most common trajectories Americans face when dying. Next, the article addresses the financial and nonfinancial barriers individuals face in obtaining quality end-of-life care. Finally, Dr. Cantor concludes with a vision of what palliative care should be like and suggests steps individuals can take to implement that vision.

Most Americans have not given much thought to either how they will die, or the kinds of services and support they will need while coping with the chronic diseases that will eventually kill them. Due to this lack of foresight, our health care and social systems are not prepared to deal with the needs of either the dying or their families. As a result, Americans continue to die while suffering unnecessarily from pain. In addition, end-of-life care bankrupts families. Overall, the health care system lacks professionals skilled in the care of dying patients. We must make tough choices and difficult changes now to improve our system of care for the chronically ill and dying.

This article explains the need for changes and suggests ways to start improving the current system's shortcomings in caring for the chronically ill and dying. Part I explores how Americans die and how their modes of death impact the types of services needed while dying. Part II reviews the financing system for these services and the lack of financing for important types of care for frail, dying, and older individuals. Following the discussion of financial barriers to good care of the dying, part III addresses additional barriers, such as the lack of knowledge of options and the lack of a coordinated system of care. Finally, the article concludes with a vision of what palliative care should be like. It also provides a

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brief set of actions for both policymakers and individuals to use today to start improving care of the chronically ill and dying.

I. HOW AMERICANS DIE

The life expectancy of Americans has increased as sanitation and health care technology have improved. Americans live longer now than they did 100 years ago, and their causes of death have changed significantly over that time.¹ Americans are now much less likely to die at home than they were a century ago; they are also less likely to have the relatively quick exit brought by infectious disease or cancer.²

While Americans are living longer,³ they are also much more likely to have a chronic illness.⁴ Those with chronic diseases report many more days with bad physical or mental health compared to those without a chronic disease, and the impact of the chronic illness is worse if the patient is also poor, less educated, or has diabetes or heart disease.⁵

Functional impairment, or disability, accompanies aging and chronic illness. As shown in Figure 1, data from the Medicare program show that disability is relatively common among older Americans and that it increases with age. Over a quarter of Americans over sixty-five have reported restrictions on activity due to chronic conditions; older African-Americans (41.6%) and Hispanics (35.1%) are even more likely than whites (26%) to have limitations due to disabilities.⁶ Disability is felt even more keenly by the oldest Americans: almost three-fourths (73.6%) of those over eighty reported having at least one disability.⁷

1. See Joanne Lynn, M.D., Testimony Before U.S. Senate Special Committee on Aging 2 (July 17, 2000), available at <http://www.medicaring.org/educate/download/testimony.doc> (last visited Jan. 17, 2004) (testifying that most Americans will die of degenerative, disabling conditions).

2. *Id.* at 2-3.

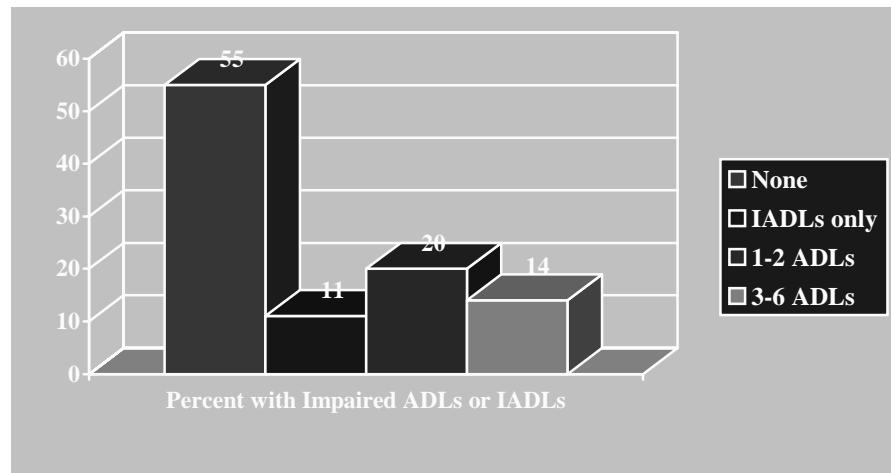
3. See NAT'L CTR. FOR HEALTH STATISTICS, HEALTH, UNITED STATES, 2002, WITH CHART-BOOK ON TRENDS IN THE HEALTH OF AMERICANS 116 (2002) (noting that the average life expectancy at birth increased from 47.3 to 76.9 years between 1900 and 2000).

4. See FOUND. FOR ACCOUNTABILITY, ROBERT WOOD JOHNSON FOUND., A PORTRAIT OF THE CHRONICALLY ILL IN AMERICA 1 (2001) (stating that about half of all Americans report having a chronic disease such as diabetes, high blood pressure, or coronary artery disease).

5. *Id.* at 5.

6. See U.S. ADMIN. ON AGING, A PROFILE OF OLDER AMERICANS: 2002 12 (2002), available at <http://www.aoa.gov/prof/Statistics/profile/2002profile.pdf> (last visited Jan. 17, 2004).

7. *Id.*

FIGURE 1: FUNCTIONAL STATUS OF MEDICARE ENROLLEES, 1998⁸

Of course, people who have illnesses and disabilities are more likely to die from their illnesses, and the death rate, therefore, increases with age.⁹ Thus, the aging of the U.S. population will lead to an increasing number of people at risk for death and a rising overall number of people who will die in the coming years. As shown in Figure 2, according to the Office of the Actuary of the Social Security Administration, the number of Americans who die each year will likely increase almost thirty percent, from 2.4 million in 1996, to 3.1 million in 2020.¹⁰

These changes in both how and when Americans die have profound implications for how our health care and social support systems should be structured. Unfortunately, our society is ill-equipped to deal with the increasing number of disabled and dying people. The first “report card” on the general state of palliative care services in the United States found that care services, which vary from state to state and within states, need to be significantly improved.¹¹ For example, only about twenty-five percent of deaths occur at home, even though seventy percent of Americans prefer to die at home.¹² Further, about half of all deaths occur in hospitals, but less than sixty percent of hospitals in any state offer specialized services for the dying.¹³ Additionally, the number of health care profes-

8. See CTRS. FOR MEDICARE & MEDICAID SERVS., MEDICARE CHARTBOOK (2001).

9. See NAT'L CTR. FOR HEALTH STATISTICS, *supra* note 3, at 137 (noting that the death rate rises from 5.7% per year for those between ages sixty-five and seventy-four to over fifteen percent per year for those over eighty-five).

10. See KAREN GILLESPIE, LAST ACTS FINANCIAL TASK FORCE, THE CHALLENGE OF END-OF-LIFE CARE: MOVING TOWARD METANOIA? 2 (1998).

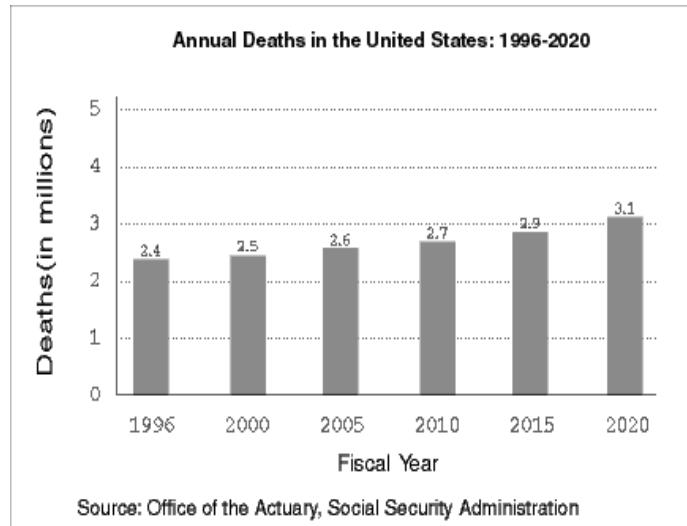
11. See LAST ACTS COALITION, MEANS TO A BETTER END: A REPORT ON DYING IN AMERICA TODAY 47 (2002).

12. *Id.* at 13.

13. *See id.* at 21.

sionals trained to care for the needs of the dying is small and inadequate.¹⁴

FIGURE 2: DEATHS IN THE U.S. 1996–2020¹⁵



In addition to these systemic problems, most Americans do not understand how we will die. Only a small percentage will die suddenly.¹⁶ Most will follow one of three possible trajectories of illness before death: the relatively quick decline and death typified by patients with aggressive cancer; the waxing and waning course of patients with organ failure; or the slow downward trajectory of older patients who die from frailty due to multiple illnesses or dementia.¹⁷ Figure 3 illustrates these common trajectories that people experience before they die.

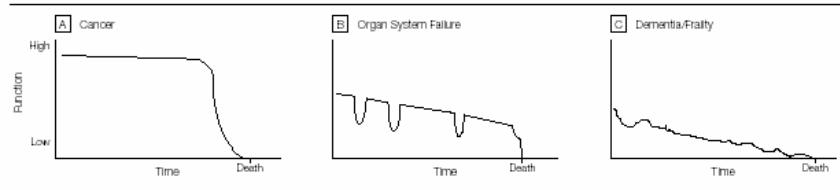
14. *Id.* at 38.

15. *Id.* at 3.

16. *See id.* at 1.

17. See Joanne Lynn, *Serving Patients Who May Die Soon and Their Families*, 285 JAMA 925, 925–32 (2001).

FIGURE 3. GENERAL TRAJECTORIES OF FUNCTION AND WELL-BEING OVER TIME IN EVENTUALLY FATAL CHRONIC ILLNESSES¹⁸



Source: Joanne Lynn, *Serving Patients Who May Die Soon and Their Families*, 285 JAMA 925 (2001). Reprinted with permission.

Graph A shows the typical course for people who have lung cancer or other rapidly growing cancers for which there are minimally effective treatments. These people have a much quicker and more predictable course before death. A patient with this type of disease does relatively well and has a gradual decline in function until the late stages of the disease, when there is a drastic, sudden decline as the disease overwhelms the patient. Predicting the needs of patients with these types of cancers is easier than for other patients, and hospice care and palliative care services are typically used for the last six months of life.¹⁹ Given the rapid decline at the end of these patients' lives, the six-month period when hospice is needed is easier to predict than for patients with chronic disease; therefore, it is easier to plan the types of services needed for these patients.

Graph B shows the common pathway for the many people who suffer from chronic diseases, such as congestive heart failure. These patients go through periods when they are relatively healthy, then have an exacerbation that results in functional decline and, frequently, hospitalization, before returning to a functional status close to what they enjoyed prior to the exacerbation. The timing of death is hard to predict: in one large study of patients with a prognosis of six months or less, physicians did no better than fifty-fifty in prognosticating whether a patient would survive to discharge.²⁰ Surprisingly, physician judgment turned out to be the most accurate predictor, even better than measures of disease severity.²¹

Graph C shows the course for patients who either have dementia or who are frail. As shown in the graph, demented patients, especially those with Alzheimer's Disease, have a chronic, progressive disease that

18. *Id.*

19. See *id.* at 927–28, 930.

20. *Id.* at 930–31.

21. See Ellen Fox et al., SUPPORT Investigators, *Evaluation of Prognostic Criteria for Determining Hospice Eligibility in Patients with Advanced Lung, Heart, or Liver Disease*, 282 JAMA 1638, 1638–45 (1999).

slowly, but inexorably, causes decline in function and then death. Similarly, patients who have a number of chronic illnesses that in combination cause functional decline and impairment also face a slow decline and eventual death.

The unpredictable timing of death, coupled with the gradual decline and the years of disability, mean that both patients with chronic diseases and those with dementia or frailty will need varying types of care over a period of years. Unfortunately, the type of care needed and the trajectory of the illness from one day to the next will be difficult to predict. Further, the lack of continuity of care and financial disincentives that limit provision of chronic care make getting needed care difficult, even if it is covered by insurance or a government program.

II. FINANCING END-OF-LIFE CARE

Financing for End-of-Life (EoL) care is inadequate. As a result of caring for a loved one with a chronic or terminal illness and being forced to pay for EoL care, many families end up bankrupt or financially devastated.²² Overall, sources of financing for patients with chronic and life-threatening diseases are limited, even for patients covered by private insurance, Medicare, or Medicaid.²³

There is no reliable national source of data on what is spent on EoL care, but it is clear that this care is expensive. The Medicare program spends over a quarter of its budget on paying for care for those in the final year of life and that number has not changed significantly in the past twenty years.²⁴ Given that seventy percent of the deaths in the United States occur in people over sixty-five,²⁵ and that dying patients are often treated with expensive technologies in hospital settings, it is not surprising that such a large percentage of the Medicare budget is spent on people who are dying.

These large Medicare expenditures occur despite a financing system that sometimes serves to reduce access to EoL services. Financing of hospice services is a good example of the systemic financial difficulties in EoL care, even when there are government or private insurers willing to

22. See Kenneth Covinsky et al., *The Impact of Serious Illness on Patients' Families*, 272 JAMA 1839, 1841-44 (1994) [hereinafter Covinsky et al., *Impact*]; Kenneth Covinsky et al., SUPPORT Investigators, *Is Economic Hardship on the Families of the Seriously Ill Associated with Patient and Surrogate Care Preferences?*, 156 ARCHIVES OF INTERNAL MED. 1737, 1737-41 (1996) [hereinafter Covinsky et al., *Economic Hardship*]; Ezekiel Emanuel et al., *Assistance from Family Members, Friends, Paid Care Givers, and Volunteers in the Care of Terminally Ill Patients*, 341 NEW ENG. J. MED. 956, 956 (1999); Ezekiel J. Emanuel et al., *Understanding Economic and Other Burdens of Terminal Illness: The Experience of Patients and Their Caregivers*, 132 ANNALS INTERNAL MED. 451, 451-59 (2000) [hereinafter Emanuel et al., *Understanding Burdens*].

23. Covinsky et al., *Impact*, *supra* note 22, at 1842.

24. See COMM. ON CARE AT THE END OF LIFE, INST. OF MED., APPROACHING DEATH: IMPROVING CARE AT THE END OF LIFE 154 (Marilyn J. Field & Christine K. Cassel, eds., 1997), available at <http://www.ama-assn.org/amednews/2002/06/10/gvsd0610.htm> (last visited Jan. 20, 2004).

25. *Id.* at 155.

pay. Hospice, a program for terminally ill patients who are close to the end of life, was initially designed for cancer patients who are functionally intact and then have a relatively fast and brief period of decline and disability before death.²⁶ Under the Medicare hospice benefit, the model for most payers, eligibility is predicated on having a prognosis of less than six months to live.²⁷ If a person meets this criterion, then they receive a comprehensive package of services, including care coordination, home care (e.g., nurses, homemakers, physical therapy, and counseling), medications, and bereavement care for family members after the patient has passed away.²⁸ Although there are some hospice facilities, hospice services are usually delivered in the patient's home.

Most hospice care in the United States is financed by Medicare, which pays for seventy-five percent of hospice care, with private insurance covering twelve percent, and Medicaid and donations each covering about seven percent.²⁹ The difficulties associated with the Medicare benefit are also typical for other payers who follow the Medicare model. Under Medicare, the hospice receives a set amount of dollars per day, regardless of the actual cost to deliver the package of services required by the hospice program.³⁰ Medicare beneficiaries who activate their hospice benefits are required to forego other Medicare benefits for treatment of the terminal illness.³¹ This works well for many people because hospice covers the cost of medications, which is not part of the standard Medicare benefits package.³² Sometimes, however, a patient receives expensive chemotherapy for treatment of symptoms or needs costly radiation therapy to alleviate pain, which some hospices refuse to provide or limit the types and extent of care they offer.³³ The financing model of hospice services can thus reduce access to care and make it more financially beneficial for hospitals and other providers to continue providing aggressive care since it is not capped and will be fully reimbursed.

In addition, it can be difficult to satisfy the requirement for a prognosis of less than six months, especially for patients with organ failure or dementia, diseases with slow, lengthy declines that make prognosis difficult. Physicians and hospices have been investigated for fraud when pa-

26. See Lynn, *supra* note 17; see also JOANNE LYNN ET AL., IMPROVING CARE FOR THE END OF LIFE § 14.0 (2000), available at <http://www.medicaring.org/educate/navigate/sourcebook.html> (last visited Oct. 6, 2003).

27. See NAT'L HOSPICE FOUND., HOSPICE CARE AND THE MEDICARE HOSPICE BENEFIT 3 (2000).

28. *Id.* at 4.

29. See STATE INITIATIVES IN END-OF-LIFE CARE, ISSUE NO. 11, HOSPICE CARE PART I: A POLICYMAKER'S PRIMER ON HOSPICE CARE 4 (Aug. 2001).

30. *Id.* at 6.

31. See NAT'L HOSPICE FOUND., *supra* note 27, at 3.

32. *Id.* at 4.

33. See Lynn, *supra* note 17, at 928.

tients were still receiving hospice benefits after the initial six month period.³⁴

Financing of care for nonhospice services at the end of life is similarly problematic. Even when patients have insurance, it often does not cover some of the important services needed by patients with terminal illnesses and chronic diseases.³⁵ The Medicare and Medicaid programs began in 1965 to cover older and poor Americans, respectively.³⁶ The federal government finances Medicare, which currently provides care for more than forty million beneficiaries.³⁷ Most of Medicare's beneficiaries are over sixty-five, but some are permanently and significantly disabled.³⁸ Medicare primarily finances hospital care, but it also covers physician services and nursing home or home care if it is related to an episode of acute illness.³⁹ Medicare does not yet pay for medications, except in special circumstances such as an inpatient stay.⁴⁰ In addition, beneficiaries have to pay significant co-pays and premiums.⁴¹ These premiums and co-pays can be so expensive that many people purchase "Medigap" policies to cover these extra costs.⁴² Medicare beneficiaries can choose managed care plans that have lower out-of-pocket costs, but many previously available plans have dropped out of the Medicare program due to inadequate reimbursements.⁴³

The Medicaid program differs from Medicare in several important ways. First, a combination of federal and state dollars fund Medicaid, giving state policymakers significant influence over eligibility criteria and what, if any, benefits are offered in addition to those mandated by the federal government.⁴⁴ Medicaid pays for hospital care, physician services, and the other Medicare benefits, but the hospice benefit varies

34. See Publication of the Medicare Advisory Bulletin on Hospice Benefits, Office of the Inspector Gen., U.S. Dep't of Health and Human Servs., 60 Fed. Reg. 55,721 (Nov. 2, 1995).

35. See Lynn, *supra* note 17, at 926.

36. See Ctrs. for Medicare & Medical Servs., Medicare Information Resource, at <http://cms.hhs.gov/medicare/> (last visited Sept. 15, 2003).

37. Healthcare Leadership Council, Medicare 101: What Is Medicare and How Does It Work?, at http://www.hlc.org/Medicare_101.pdf (last visited Oct. 6, 2003).

38. See Ctrs. for Medicare & Medicaid Servs., Medicaid Enrollment—Aged Beneficiaries as of July 2001, at <http://cms.hhs.gov/statistics/enrollment/st01aged.asp> (last modified Dec. 3, 2002); Ctrs. for Medicare & Medicaid Servs., Medicare Enrollment—Disabled Beneficiaries as of July 2001, at <http://cms.hhs.gov/statistics/enrollment/st01dis.asp> (last modified Dec. 3, 2002).

39. A complete discussion of the Medicare program is beyond the scope of this article. For a brief yet comprehensive explanation of the Medicare program, see CTRS. FOR MEDICARE & MEDICAID SERVS., MEDICARE AND YOU 2003 5–9 (2003).

40. Healthcare Leadership Council, *supra* note 37, at 2.

41. CTRS. FOR MEDICARE & MEDICAID SERVS., *supra* note 39, at 8.

42. See Medicare, Medicare Plan Choices, at <http://www.medicare.gov/choices/overview.asp> (last visited Oct. 6, 2003).

43. See Markian Hawryluk, *House Bill Attempts Medicare Managed Care Rescue: President Bush and House Republicans Seek to Increase Funding for a Program on the Brink*, AM. MED. NEWS, June 10, 2002, available at <http://www.ama-assn.org/public/journals/amnews/hawryluk>.

44. CTR. FOR HEALTH CARE STRATEGIES, INC., CASE FOR CLINICAL PHARMACY MANAGEMENT, available at http://www.chcs.org/publications/pdf/ips/cpmi_case.pdf (last visited Jan. 17, 2004).

slightly from state to state.⁴⁵ The Medicaid program also pays for several benefits not covered by Medicare. For example, Medicaid covers the costs of medication.⁴⁶ Some chronic home care services and chronic nursing home care are covered, as well.⁴⁷ Unlike Medicare, access to Medicaid is limited to people who are poor and have income and assets below a state-established level, which must be within federal guidelines.⁴⁸ Many people in nursing homes go on Medicaid after "spending down," that is, after they have spent enough of their assets to meet the eligibility level set by the state Medicaid program.⁴⁹

The inadequate financing system for patients with terminal or chronic illnesses results in patients and families paying for care, causing significant financial hardships. Evaluation of the Medicare program has shown that Medicare pays for barely more than half of the health care costs of people in their last year of life.⁵⁰ One study of caregivers of people with terminal illnesses found that, while between seventeen and twenty-eight percent said that they spent more than ten percent of their household income on health costs in addition to the costs of health insurance premiums, ten to sixteen percent of respondents said they had to take on an additional job or take out a loan or mortgage to pay for health care costs.⁵¹ Another study found that in twenty percent of the studied cases, a family member had to quit work or make another major life change to provide care for the patient, that thirty-one percent of families reported loss of most or all of the family savings, and that twenty-nine percent reported loss of the major source of income.⁵² Because the financing system does not pay for the care provided by families and friends, the financial impact on families was worse when the ill person needs more help.⁵³ EoL care, therefore, obviously places a significant financial burden on the dying and their families.

III. OTHER BARRIERS TO END-OF-LIFE CARE

In addition to financial burdens, these terminally and chronically ill individuals and their families also face other important barriers to adequate EoL care. The most significant nonfinancial barriers are lack of knowledge about choices related to EoL care, inadequate coordination of care, and a society that is in denial of aging and mortality and, conse-

45. See JANE TILLY & JOSHUA M. WIENER, MEDICAID AND END-OF-LIFE CARE 11-12 (2001).

46. Ctrs. for Medicare & Medicaid Servs., Medicaid Services, at <http://cms.hhs.gov/medicaid/mservice.asp> (last modified Sept. 3, 2003).

47. *Id.*

48. Ctrs. for Medicare & Medicaid Servs., Welcome to Medicaid: Site for Consumer Information, at <http://cms.hhs.gov/Medicaid/default.asp> (last modified Oct. 28, 2003).

49. *Id.*

50. See COMM. ON CARE AT THE END OF LIFE, *supra* note 24, at 155.

51. See Emanuel et al., *Understanding Burdens*, *supra* note 22.

52. See Covinsky et al., *Impact*, *supra* note 22, at 1839.

53. See Emanuel et al., *supra* note 22, at 457.

quently, values and pays more for high-tech, rather than "high touch" interventions.

Most Americans are not aware of the three common trajectories of death or that most of us will die of a chronic illness when we are old and frail.⁵⁴ Because most Americans die from illnesses causing disability and functional impairment, they frequently need assistance with activities of daily living. Further, the severity of the illness affects the amount of help needed.⁵⁵ Individuals may require different types of help, ranging from paying bills and buying food, to bathing, eating, and dressing. While family members and friends provide the majority of this kind of help, for people who lack caregivers, help may be too expensive to obtain or otherwise unavailable.

The lack of a coordinated system of care for people with disabilities exacerbates the lack of knowledge of choices and the realities of dying after struggling with chronic illnesses. Assistance for care of people with chronic illnesses or the dying may come from a wide array of agencies and programs. For example, home care agencies provide skilled nursing care and homemakers who can do chores, other agencies provide meals-on-wheels, and yet another agency provides care coordination or financial assistance. Patients enrolled in hospice, however, have the benefit of coordinated care from one provider. Unfortunately, hospice benefits only a relatively small percentage of the large number of patients with chronic diseases.⁵⁶

The American health care system is actually a collection of a wide variety of health care organizations and providers sell their services to various payers. Patients are free to choose from among this array of providers, but the lack of coordination can make it difficult for patients to find out what services are available and for providers to communicate with each other. Unfortunately, while care may be provided by multiple physicians and hospitals, care coordination is not universally available. As the complexity of the medical illness increases, the need for coordination of the growing number and intensity of services also increases. Thus, the second major barrier to adequate EoL care is that there is no coordinated system of care available to people who are dying.

The American health care system also pays more for invasive, high-tech services rather than for services geared to the needs of people with chronic diseases. A recent article compared the costs of providing usual care versus good EoL care, which is coordinated and allows patients to die at home.⁵⁷ The article describes the case of Mrs. Smith, a seventy-

54. See Lynn, *supra* note 17, at 930.

55. See Covinsky et al., *Impact*, *supra* note 22, at 1842.

56. See LAST ACTS COALITION, *supra* note 12, at 18.

57. See Joanne Lynn et al., *Financing of Care for Fatal Chronic Disease: Opportunities for Medicare Reform*, 175 W.J. MED. 299 (2001), available at <http://www.wjm.com/cgi/reprint/175/5/299.pdf> (last visited Dec. 18, 2003).

eight year old with mild heart failure, who was also the caregiver for her eighty-four-year-old husband, who was mildly demented and needed help with transfers, bathing, and dressing after suffering a disabling stroke.⁵⁸ Mrs. Smith was diagnosed with breast cancer and, while she was undergoing treatment, Mr. Smith's condition worsened and he was admitted to a local nursing home.⁵⁹ A few months after moving to the nursing home, he developed a serious urinary tract infection and died in the intensive care unit.⁶⁰ Meanwhile, Mrs. Smith's heart failure worsened, making it more difficult for her to walk.⁶¹ She subsequently fell, broke a hip, and ended up in a nursing home.⁶² A few months later, she had a severe flare-up of her heart failure and died in the intensive care unit of the local hospital.⁶³

In a different system, things might have turned out better. Mrs. Smith's physician could have recognized the precarious situation when the breast cancer diagnosis was made and arranged for a case manager, who could have contacted the Smiths' church for help. The church may have arranged for the city to repair the Smiths' apartment and provide home health aides. In this improved scenario, Mr. Smith may have died at home with home care after having another stroke. After his death, Mrs. Smith might have moved to subsidized housing with home help and died quietly one night a few years later. While this case scenario does take liberties with the way the Smiths' health deteriorated, it points out that there were opportunities for interventions that would have reduced hospitalization and enabled the Smiths to die at home, rather than in an institution.

In discussing the two scenarios, the article compares their costs and concludes that, while it is much cheaper for Medicare to have the Smiths die at home rather than use expensive hospital services, the providers would lose money if the Smiths died at home.⁶⁴ Financial incentives currently encourage providers to offer higher intensity, more expensive care. One explanation for this is that our society values these interventions more than merely letting nature take its course. Therefore, we pay more for high-tech services, such as intensive care unit stays, while paying less or not paying at all for simpler services, such as home health aides who can bathe the patient. The American emphasis on cure over care may also reflect a deep-seated denial of aging and the inevitability of death. Failure to address these issues in advance can lead to continuation of the current system of inadequate care.

58. *Id.* at 299.

59. *Id.*

60. *Id.*

61. *Id.*

62. *Id.*

63. *Id.*

64. *Id.* at 300.

IV. THE WAY FORWARD

It is possible—and necessary—for Americans to work together to improve our system of care for those with chronic diseases and terminal illnesses. The lack of knowledge about needed services, financial burdens, the fragmented system of care, and American society's difficulty facing death are significant barriers to improvement, but they can be overcome. Several groups of experts in palliative care have created action plans that offer guidance for every American to take positive steps toward change.

The Last Acts campaign, funded by the Robert Wood Johnson Foundation, is a national effort to improve EoL care.⁶⁵ The Last Acts Task Force on Palliative Care developed a statement of five principles of palliative care that explain what palliative care should be like. The first principle is that palliative care “respects the goals, likes and choices of the dying person” and makes sure that the patient’s wishes shape the care received.⁶⁶ The second is that “palliative care looks after the medical, emotional, social and spiritual needs of the dying person” to assure that patients do not die alone, that families are supported as the illness progresses, and to help people reflect upon their lives.⁶⁷ The third principle is that palliative care should “[support] the needs of the family members” by assisting family members coping with emotional pain, offering respite from caregiving, assisting with the financial impact of caregiving, and helping with bereavement.⁶⁸ Fourth, caregivers should “[help patients] gain access to needed health care providers and appropriate care settings” by bringing together a multidisciplinary care team and helping to assure access to hospitals, home care, hospice, or whatever services are needed.⁶⁹ Finally, good palliative care “builds ways to provide excellent care at the end of life” by assuring that providers are educated, that policies support and encourage excellent EoL care, and that there is adequate funding for these services.⁷⁰

Making these five principles of palliative care a reality is going to be difficult; however, with concerted action, they can be achieved. Dr. Joanne Lynn and others at the Washington Home Center for Palliative Care Studies⁷¹ have developed a set of promises that should be made to all patients with chronic illness and to those who are dying. The seven promises include: good medical treatment, that the patient will never be

65. *Id.*

66. LAST ACTS TASK FORCE ON PALLIATIVE CARE, LAST ACTS COALITION, PRECEPTS OF PALLIATIVE CARE 2 (1997), available at <http://www.lastacts.org/docs/profprecepts.pdf> (last visited Jan. 17, 2004).

67. LAST ACTS COALITION, *supra* note 12, at front inside cover.

68. *Id.*

69. *Id.* at back inside cover.

70. *See id.*

71. *See generally* The Washington Home Center for Palliative Care Studies, at <http://www.medicaring.org> (last visited Dec. 1, 2003).

overwhelmed by symptoms, that the care provided will be comprehensive and that continuity of care will be assured, that there will be planning so that there are no surprises, that care will be customized to reflect patient preferences, that the family is part of care, and, finally, that patients will be empowered to make the best of every day.⁷²

These seven promises—and the five principles—focus on overcoming the many barriers to good EoL care and outline a vision for how palliative care should be provided. What can be done to assure that the principles and promises are more than abstract theories? First, we need to educate health care providers, patients, and families about the tough choices ahead.⁷³ Both professionals and lay people need to understand the options for individual care and for our system, as a whole. Second, we need to make policy changes to enhance and improve our current system of care. For example, Medicare and Medicaid policies should be modified so that there are incentives to provide the kind of care that both meets the needs of patients and is consistent with the principles of palliative care. In addition, adequate financing should be put into place to reduce the potentially devastating economic consequences of caring for a sick family member, and payment mechanisms should encourage chronic disease management and provision of palliative care. Third, everyone should use advance care planning tools.⁷⁴ Individuals need to make care plans for the end of life so that both they and their families are aware of their preferences should they face a terminal illness and be unable to speak for themselves.

Now is the time for action to improve our system of care for people with chronic and life-threatening illnesses. Individuals can take steps to make a difference.⁷⁵ For example, individuals should find out what palliative care services their physicians offer. They should also ask their employers and local Chambers of Commerce what is being done to support employees who are caring for aging or dying relatives or friends. Another possible step is contacting local, state, and federal representatives to ask them what they are doing to improve the system. Finally, concerned individuals should also consider writing a letter to the editor

72. See Lynn, *supra* note 1, at 10.

73. There are a number of helpful websites with information about palliative care and hospice. See, e.g., The Washington Home Center for Palliative Care Studies, *supra* note 71; End of Life/Palliative Education Resource Center (EPERC), *at* <http://www.eperc.mcw.edu> (last visited Dec. 1, 2003); Growth House, Inc., *at* <http://www.growthhouse.org> (last visited Dec. 1, 2003); Last Acts Campaign to Improve End of Life Care, *at* <http://www.lastacts.org> (last visited Dec. 1, 2003); and The Nat'l Hospice & Palliative Care Org., *at* <http://www.nhpco.org> (last visited Dec. 1, 2003).

74. For tools to guide consumers about making health care decisions, see AM. BAR ASS'N COMM'N ON LAW & AGING, CONSUMER'S TOOL KIT FOR HEALTH CARE ADVANCE PLANNING, *available at* <http://www.abanet.org/aging/toolkit/home.html> (last visited Sept. 17, 2003). For tools for attorneys counseling clients about how they should make advance care plans, see AM. BAR ASS'N COMM'N ON LAW & AGING, LAWYER'S TOOL KIT FOR HEALTH CARE ADVANCE PLANNING (2000).

75. See AM. FOR BETTER CARE OF THE DYING, THE AGITATOR'S GUIDE: TWELVE STEPS TO GET YOUR COMMUNITY TALKING ABOUT DYING, reprinted in LYNN ET AL., *supra* note 26, § 12.8; see also LAST ACTS COALITION, *supra* note 12, at 50.

of the local paper or an op-ed piece to raise awareness of the need to improve our system of palliative care.

As our society ages and the prevalence of chronic disease and disability increases, Americans will have to make tough choices about how to allocate resources and change our health care system. While making these choices will not be easy, both choices and changes must be made because doing nothing will only guarantee that the problems with the current system will continue.