

MEDICARING: QUALITY END-OF-LIFE CARE

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INTRODUCTION

End-of-life care, physician-assisted suicide, and decision-making capacity have garnered increased attention as of late. The United States Supreme Court recognized the import of such controversial and compelling issues when it considered the question of the constitutionality of physician-assisted suicide in June, 1997.¹ In *Washington v. Glucksberg*,² the Court determined that, contrary to a finding by the Ninth Circuit Court of Appeals,³ the right to physician assistance in suicide was not one inherent to all Americans under the Fourteenth Amendment's Due Process Clause.⁴ The Court similarly rejected the Equal Protection argument that prevailed in the Second Circuit⁵ and reaffirmed that the distinction between forgoing life-sustaining treatment and obtaining physician assistance in suicide is a valid one.⁶ In a unanimous decision, the U.S. Supreme Court sent the question of assisted suicide to state legislatures, simultaneously igniting a debate not only in state congressional offices but also in hospital ethics committees, classrooms, newspaper editorial pages, and workplaces across the country.

The Supreme Court's ruling notwithstanding, almost two-thirds of respondents in most polls consistently seem to want a suicide option.⁷ These high numbers signify a clear rejection of the status quo. Those on both sides of the physician-assisted suicide debate find some

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1. See *Washington v. Glucksberg*, 117 S. Ct. 2258 (1997); *Vacco v. Quill*, 117 S. Ct. 2293 (1997).

2. 117 S. Ct. 2258.

3. See *Compassion in Dying v. Washington*, 79 F.3d 790, 793-94 (9th Cir. 1996).

4. See *Glucksberg*, 117 S. Ct. at 2262.

5. See *Quill v. Vacco*, 80 F.3d 716, 731 (2d Cir. 1996).

6. See *Vacco*, 117 S. Ct. at 2297-98.

7. See John La Puma, *Physician-Assisted Suicide, Managed Care: Unhappy Bedfellows, a Match Made in Hell*, *MANAGED CARE*, Aug. 1997, 125, 125; Robert J. Blendon et al., *Should Physicians Aid Their Patients in Dying?: The Public Perspective*, 267 *JAMA* 2658, 2659 (1992).

commonality in the recognition that requests for assistance in death are usually a result of deficiencies in the health care system.⁸ Our health care system's ability to provide technological responses to illness and the often aggressive care people receive at the end of life leave many people "fearful that the combination of old age and modern medicine will inflict on them a dying that is more protracted and, in some ways, more difficult than it would have been a few decades ago."⁹ Problems in end-of-life care are increasingly well documented, ranging from undertreated pain to unwanted or futile treatments to prolong life.¹⁰ Unfortunately, much of the public sees these as inevitable impositions and technological assaults — hence the public's interest in the assisted suicide debate.¹¹

Good care of the dying calls for interdisciplinary care teams, continuity and coordination of care, integration of diverse services delivered across a variety of settings and financing arrangements, and changes in the orientation and culture of providers and public alike; not yet achieved under our current health care system. This paper will examine some of the changes in our social and medical circumstances which have triggered the question of the individual's right to physician-assisted suicide and provides a programmatic alternative for ensuring that more of us can be comfortable and confident as we face the ends of our lives.

Specifically, Part I will describe current end-of-life care options. Part II will describe *Medicaring* projects which we argue would provide an array of services appropriately tailored to persons with serious chronic illnesses facing the ends of their lives. Finally, we conclude that such projects would provide such care without a parallel increase in costs.

I. CURRENT END-OF-LIFE CARE OPTIONS

Advances in health care and improvements in public health have enabled most Americans to live longer and to survive many life-threatening events such as premature birth, heart attacks, and traumatic injury — major killers just a few decades ago.¹² Americans can typically

8. See COMMITTEE ON CARE AT THE END OF LIFE, INSTITUTE OF MEDICINE, *APPROACHING DEATH: IMPROVING CARE AT THE END OF LIFE* 15-16 (Marilyn J. Field & Christine K. Cassel eds., 1997) (explaining the far-reaching recognition of the advent of institutionalized death) [hereinafter *IMPROVING CARE AT THE END OF LIFE*].

9. *Id.* at 14.

10. *See id.*

11. *See id.* at 14-15.

12. *See id.* at 14.

now expect to live well into their eighth decade (median life expectancy has reached 79 years of age for women and 73 years of age for men).¹³ In 1900, there were just three million elderly persons (those 65 years or older), comprising just 4.1% of the population.¹⁴ By 1994, there were 33 million elderly (one in every eight Americans) — an eleven-fold increase. Those 75 to 84 years of age increased from just 1% of the population to almost 7%, a seven-fold increase. The very old (those over age 85) constitute the fastest growing segment of the entire population, rising 28% between 1990 and 1994.¹⁵

One unanticipated consequence of larger numbers of persons living into very old age has been the emergence of long-term, chronic diseases as the major pathway to disability and death.¹⁶ Until the early part of this century, death was "sudden" and could occur at any age, usually from acute infectious diseases (particularly influenza, tuberculosis, and diphtheria), accidents, and complications of childbirth.¹⁷ The average age of death in 1900 was approximately 50 years of age, whereas it is approximately 77 years of age today.¹⁸ People over the age of 65 now account for 13% of the population and over 70% of all deaths. In addition, the causes of death have changed. In an examination of 1993 Medicare claims data, Hogan found that over 80% of all decedents had one of *five* kinds of illnesses in the year before death: heart failure, chronic obstructive pulmonary disease, cancer, stroke, or dementia.¹⁹ These illnesses disproportionately affect older people²⁰ and ordinarily occasion a prolonged course of increasing disability and illness prior to death. In 1994, nearly 40% of the elderly

13. See BUREAU OF THE CENSUS, U.S. DEP'T OF COMMERCE, STATISTICAL ABSTRACT OF THE UNITED STATES 1996 88-89 (116th ed. 1996) [hereinafter STATISTICAL ABSTRACT]; Harry M. Rosenberg et al., *Births and Deaths: United States, 1995*, 45 MONTHLY VITAL STATISTICS REP., Oct. 4, 1996, at 4.

14. See Charles F. Longino, Jr., *Pressure from Our Aging Population Will Broaden Our Understanding of Medicine*, 72 ACAD. MED. 841, 842 (1997).

15. See Frank B. Hobbes, *The Elderly Population* (visited Feb. 24, 1999) <<http://www.census.gov/population/www/pop-profile/elderpop.html>>.

16. See IMPROVING CARE AT THE END OF LIFE, *supra* note 8, at 14.

17. See Judith M. Stillion, *Death in the Lives of Adults: Responding to the Tolling of the Bell*, in DYING: FACING THE FACTS 303, 304-05 (Hannelore Wass & Robert A. Neimeyer eds., 3d ed. 1995) [hereinafter DYING: FACING THE FACTS].

18. See STATISTICAL ABSTRACT, *supra* note 13, at 88-89; Robert Fulton & Julie Fulton, *A Psychosocial Aspect of Terminal Care: Anticipatory Grief*, 2 OMEGA 91 (1971).

19. Interview with Christopher Hogan, Vice President, CHPS Consulting, in Washington, D.C. (July 1997).

20. See IMPROVING CARE AT THE END OF LIFE, *supra* note 8, at 37.

population not living in institutions (12 million persons) were limited in activities of daily living by chronic conditions.²¹

Dying from chronic illnesses is very costly. Most beneficiaries in any one year have very small expenses, and a few have very large ones. In fact, most of Medicare dollars in any one year are spent on less than one-fifth of the beneficiaries. About 28% of Medicare funds are now spent on care in the last year of life,²² which is geared toward expensive, high-technology interventions and "rescue" care. Of the funds Medicare spends on patients in their last year, about 40% is spent on care given in the last 30 days of life and 50% for care in the last 60 days.²³

Although Medicare costs overall increased nearly four-fold from 1976 to 1988, Lubitz and Riley showed that dying patients utilized the same relative share of Medicare expenses and patterns of expenses.²⁴ Using data from 1979, Riley, Lubitz, and colleagues found substantial variation among diseases in costs at the end of life.²⁵ In their 1993 study, Riley and Lubitz examined the pattern of expenditures over time for the same causes of death.²⁶ These studies provide evidence that dying from certain chronic illnesses is disproportionately expensive over a long period.

Our cultural conception of dying is built upon our experience with cancer. Most patients with solid tissue cancers (e.g., lung, gastrointestinal, renal) have a long period of functional stability despite progressive illness and a relatively predictable, brief final course of decline, or terminal phase,²⁷ usually lasting less than six weeks. The referral to hospice, when it occurs, happens after the start of a failing phase that is clearly marked. This failing phase, usually one month

21. See CHRONIC CARE IN AMERICA: A 21ST CENTURY CHALLENGE, 27 (Robert Wood Johnson Foundation ed. 1996).

22. See Muriel Gillick, *The High Costs of Dying: A Way Out*, 154 ARCHIVES OF INTERNAL MED. 2134, 2134 (1994); see also Nelda McCall, *Utilization and Costs of Medicare Services by Beneficiaries in Their Last Year of Life*, 22 MED. CARE 329, 330 (1984) (explaining a pattern of high medical care expenditures in the last year of life); William D. Spector & Vincent Mor, *Utilization and Charges for Terminal Cancer Patients in Rhode Island*, 21 INQUIRY 328 (1984) (explaining a study showing that medical care costs stem mainly from the final months of life, and are dominated by hospital charges).

23. See Gillick, *supra* note 22, at 2134.

24. See James D. Lubitz & Gerald F. Riley, *Trends in Medicare Payments in the Last Year of Life*, 328 NEW ENG. J. MED. 1092, 1094 (1993).

25. See Gerald Riley et al., *The Use and Costs of Medicare Services by Cause of Death*, 24 INQUIRY 233, 237 (1987).

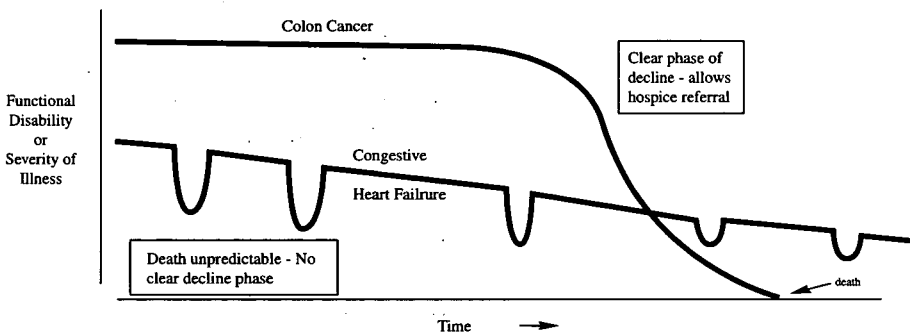
26. See Lubitz & Riley, *supra* note 24, at 1092.

27. See IMPROVING CARE AT THE END OF LIFE, *supra* note 8, at 28-29.

ahead of death, is found in all countries with hospice services.²⁸ Thus, in the cancer paradigm, the *disease* prompts the “transition from cure to comfort care,” at a time when the patient is clearly failing.

In contrast, chronic illnesses, such as congestive heart failure (CHF) or chronic obstructive pulmonary disease (COPD), do not fit the course of most cancer deaths.²⁹ Such diseases, even at the advanced stages, produce trajectories that usually have no identifiable “failing” phase and have no clear physiological events which would lead doctors (or family members) to label such a patient as “dying,” even when he or she is extremely disabled. (See Figure 1).

FIGURE 1³⁰
ILLNESS IMPACT TRAJECTORY



Chronic illnesses have a gradual onset of daily symptoms, unfold over a long period of time, and often do not have a single unambiguous cause.³¹ Frequently, they have multiple and shifting responses to treatments, produce trajectories of illness that defy prediction, and the costs of their care are high. For example, when CHF patients are not experiencing an exacerbation of their disease, they say they are fine and feel well.³² They have adapted to activity and diet restrictions and do not perceive their limitations as active illness. Death from

28. Interview with Vincent Mor, Director, Center for Gerontology and Health Care Resources, Brown Univ., in Washington, D.C. (June 1998).

29. See THE CENTER TO IMPROVE CARE OF THE DYING, GEORGE WASHINGTON UNIVERSITY MEDICAL CENTER, SECOND ANNUAL ACTIVITIES REPORT 15 (1997); see also IMPROVING CARE AT THE END OF LIFE, *supra* note 8, at 29 (explaining sudden death from an unexpected cause).

30. See Andrew A. Skolnick, *MediCaring Project to Demonstrate and Evaluate Innovative End-of-Life Program for Chronically Ill*, 279 JAMA 1511, 1511 (1998) (depicting figure by Joanne Lynn & Anne M. Wilkinson).

31. See Longino, *supra* note 14, at 842.

32. See Joanne Lynn et al., *Defining the "Terminally Ill": Insights from SUPPORT*, 35 DUQ. L. REV. 311, 329-30 (1996) [hereinafter *Defining the "Terminally Ill"*] (explaining the unpredictability of death from CHF).

CHF occurs mostly from heart attacks, strokes, arrhythmias, or infections, which are quite unpredictable. Thus, death will almost always seem to be “sudden” in these patients.

The inherent unpredictability of this more common course at the end of life is illuminated by a “prognoses on the days before death” analysis from the SUPPORT study. (See Figure 2).³³ SUPPORT, the Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatments, collected data on 9,105 very sick hospitalized patients, identified problems in their care, and tried and failed to correct these problems.³⁴ Data collected in the SUPPORT study was used to generate multivariate estimates of survival prognosis.³⁵ The relationship of median estimates to time of death were examined for different diseases and for intensive care unit (ICU) settings of care.³⁶ All patients, and especially CHF patients, had substantial odds to live much longer than would have been expected by care providers, right up to the day before death.³⁷ Overall, SUPPORT patients were found to have a median 51% chance of survival for two months just one week ahead of death.³⁸ Median prognoses varied substantially among diseases: lung cancer patients had a median prognosis of 17% to live two months on the day before death and 50% chance just one week before death.³⁹ Those with CHF had a median prognosis of over 60% to live two months⁴⁰ and over 40% to live for six months on the day before death. It is unlikely that physicians, patients, or their loved ones would recognize that death is near with prognoses that so strongly suggest hope. The median patient dying in SUPPORT still had a very good chance to survive for two months, or to leave the hospital, even on the day before death — few would describe these patients as “dying.”

33. See Alfred F. Connors, Jr. et al., *A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)*, 274 JAMA 1591 (1995).

34. See *id.* at 1591. The SUPPORT study aimed to improve end-of-life decision making and reduce the frequency of a mechanically supported, painful, and prolonged process of dying. See *id.* Patients used in the study included a total of 9105 adults hospitalized in one of five teaching hospitals in the U.S. with one or more of nine life-threatening diagnoses — overall six-month mortality rate of 47%. See *id.* The study entailed a two-year prospective observational study with 4301 patients followed by a two-year controlled clinical trial with 4804 patients and their physicians randomized by specialty group to the intervention group (n=2652) or control group (n=2152). See *id.*

35. See *Defining the “Terminally Ill,” supra* note 32, at 314.

36. See *id.* at 324-27.

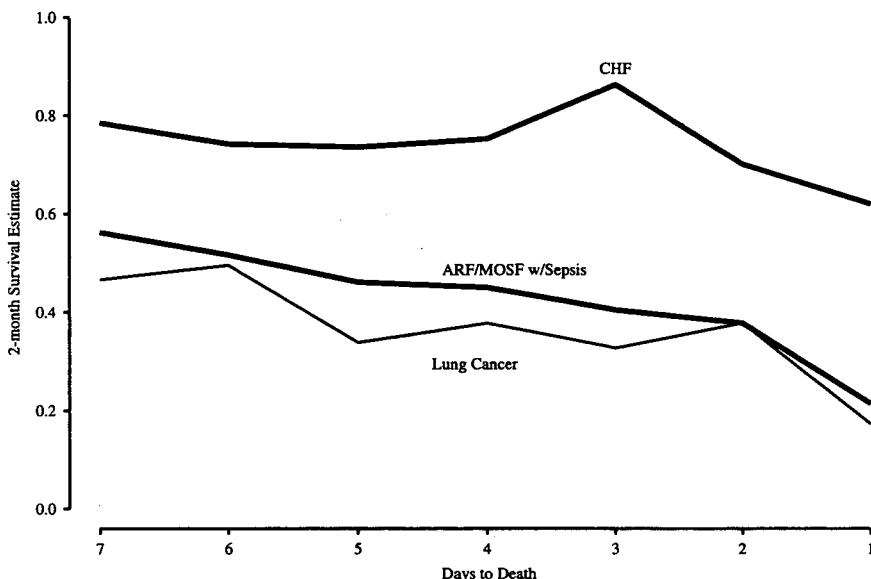
37. See *id.*

38. See *id.* at 326.

39. See *id.* at 329.

40. See *id.* at 327.

FIGURE 2
MEDIAN PROGNOSIS FOR 2-MONTH SURVIVAL



These data illuminate the current limits of our ability to predict death, even when it is very close. Despite the ability of prognostic models to estimate survival for groups of patients, these data show that there is wide variability in the actual survival time of individual patients. Many sick persons, their families, and their physicians would see these patients as in need of treatment to improve their chances. Thus, at least for advanced chronic illness, one cannot always rely upon there being a period of time in which dying is evidently near or which is long enough to allow those involved to “plan for the death.” Consequently, for those with advanced chronic illness, it may be most useful to develop parallel streams of plans: one which facilitates discussion about death and optimal support of the patient and family through to death and for the family afterward and a second set of plans which provides maximal effort to restore physiologic balance.⁴¹

Unfortunately, few medical systems accomplish this “combined” management approach to seriously ill patients; i.e., seeking survival while acknowledging and planning for the likelihood of death. With progress in medical technology has come increased specialization in health care delivery. Death, along with the rest of health care, has

41. See Joanne Lynn et al., *Prognoses of Seriously Ill Hospitalized Patients on the Days Before Death: Implications for Patient Care and Public Policy*, 5 *NEW HORIZONS* 56, 61 (1997).

become increasingly institutionalized and "medicalized."⁴² Over the last hundred years, death has been moved from the home and into institutions. In 1949, national statistics showed that 50% of all deaths occurred in institutions (39.5% in general hospitals and the rest in psychiatric and other kinds of hospitals and nursing homes);⁴³ by 1980, 74% of all deaths occurred in institutions (60.5% in hospitals and 13.5% in other institutions).⁴⁴

The extension of life expectancy and increasing medicalization of all aspects of life, including death, has presented the medical community with a challenge. The U.S. health care system has historically focused on the treatment of acute diseases, accidents, and rescue care, with cure as the goal. However, this type of care system is sadly mismatched with the needs of persons who will steadily deteriorate with a chronic illness to death. Sometimes, invasive attempts to prolong life are less preferable than supportive and palliative care might be. Finding the right combination for each patient is extremely important but also difficult to do.

Data collected in the SUPPORT study showed that half of those conscious near death were reported by family members to be in moderate to severe pain most of the time.⁴⁵ The median death in this study followed more than a week in an ICU.⁴⁶ Patients and their physicians did not routinely make plans for end-of-life care or even converse about the overall course of the disease or how to manage predictable problems along the way.⁴⁷ An order to forgo resuscitation was written, on average, only two days prior to death.⁴⁸

Moreover, individuals living with advanced and progressive chronic illness face a disastrously fragmented and disorganized health care system. Health care is organized by site of care (hospital, nursing home, clinic, etc.); treated according to disease (renal failure, heart attack, etc.); and rates of payment based on intervention (cardio-thoracic surgery, diagnostic radiology, etc.).⁴⁹ However, this is not how

42. See generally Jeanne Quint Benoliel & Lesley F. Degner, *Institutional Dying: A Convergence of Cultural Values, Technology, and Social Organization*, in DYING: FACING THE FACTS, *supra* note 17, at 117.

43. See Monroe Lerner, *When, Why and Where People Die*, in THE DYING PATIENT 21 (Orville G. Brim, Jr. et al., eds. 1970).

44. See Dwight B. Brock & Daniel J. Foley, *Demography and Epidemiology of Dying in the U.S. with Emphasis on Deaths of Older Persons*, 13 HOSPICE J. 49, 53 (1998).

45. See Connors et al., *supra* note 33, at 1594.

46. See *id.*

47. See *id.* at 1591.

48. See *id.*

49. See Mark S. Lachs & Hirsch S. Ruchlin, *Is Managed Care Good or Bad for Geriatric Medicine?*, 45 J. AM. GERIATRICS SOC'Y 1123, 1123-27 (1997); see generally R. Sean Morrison &

dying patients experience illness. Instead, advanced chronic illness is more often progressive, cumulative, multiple, and fatal.⁵⁰ These patients are ill-served by a system in which physician encounters are brief, technology is emphasized, care is uncoordinated and provided by a multitude of providers, hospitalizations and procedures cause iatrogenic illnesses, and the financial incentives of the reimbursement system favor the continued utilization of high technology procedures over relatively simple, and perhaps more appropriate, palliative measures.⁵¹ All of these factors lead to inefficiencies in service delivery, lack of continuity, and cost-increasing incentives to over-treat and over-serve patients.⁵² Moreover, the current fee-for-service system, which covers 90% of the elderly Medicare population, does not pay for the kind of care that could ensure better coordination of services and prevention of crises; nor does it pay for multidisciplinary teams of providers who could provide continuity of care across health care delivery sites and over a long period of time.⁵³

The integration of delivery and financing of healthcare under managed care arrangements represents a significant change in the health care delivery landscape. The older, not-for-profit managed care systems have been shown to create incentives for prevention, the reduction of service use when possible and cost containment without adverse effects on health outcomes.⁵⁴ However, the more recent advent of for-profit managed care is more often than not viewed as "care denying." In theory, these managed care arrangements can allow the flexibility of funding, personnel, physical plant, location, and ability to

Diane E. Meier, *Managed Care at the End of Life*, 10 TRENDS HEALTH CARE L. & ETHICS 91 (1995).

50. See generally Lachs & Ruchlin, *supra* note 49.

51. See *id.*

52. See *id.*

53. See *id.*

54. See, e.g., Nathan R. Every et al., *Resource Utilization in Treatment of Acute Myocardial Infarction: Staff-Model Health Maintenance Organization Versus Fee-for-Service Hospitals*, 26 J. AM. C. CARDIOL. 401 (1995) (concluding that physicians in staff-model health maintenance organization (HMO) hospitals use fewer invasive procedures and longer durations of stay for treatment of patients with acute myocardial infarction than physicians in fee-for-service hospitals); Sheldon Greenfield et al., *Variations in Resource Utilization Among Medical Specialties and Systems of Care: Results from the Medical Outcomes Study*, 267 JAMA 1624 (1992) (examining whether specialty and system of care exert independent effects on resource utilization); Willard G. Manning, *A Controlled Trial of the Effect of a Prepaid Group Practice on Use of Services*, 310 NEW ENG. J. MED. 1505 (1984) (finding hospitalization rates under an HMO-type system to be 40% lower than those under a fee-for-service system); see also Sheldon M. Retchin & Jeanette Preston, *Effects of Cost Containment on the Care of Elderly Diabetics*, 151 ARCHIVES OF INTERNAL MED. 2244 (1991) (concluding, in study of diabetic HMO enrollees, that the quality of diabetic care under HMOs was similar to that under a fee-for-service system).

track patients necessary for more systematic planning and delivery of services, especially for geriatric patients and those with advanced chronic illnesses. Nevertheless, the principles of "gatekeeping," the potential for the reduction of beneficial, as well as unnecessary tests and procedures, and the pressures for cost containment (i.e., short lengths of stay, etc.) raise concerns about the quality of care that enrollees may receive.

Finally, the existing reimbursement system, whether fee-for-service or managed care, has provided little incentive for providers to focus on elements of a good end-of-life care delivery model, such as functional status, continuity, or prevention. Pain management is routinely ignored and providers are rarely continuous across time or sites. End-of-life care often falls to physician specialists focused on rescue (e.g., oncologists, cardiologists) when multi-disciplinary teams attentive to nursing and social issues could provide more effective and more reliable supportive care. All the evidence suggests that patients and their families have little ability to reshape care to better meet their needs compared with the influence of provider supply and established care patterns.⁵⁵

For persons with less serious or more curable illnesses, these shortcomings of patient care might be considered to be minor annoyances (e.g., the inconvenient location of care services) or merely amenities (e.g., spiritual counseling, dignity of the person, respect for patient's wishes). In the context of a fatal illness, however, these issues acquire paramount importance. Yet, in the current system of care, we do not hold anyone accountable for these shortcomings nor are they measured or compared.⁵⁶ Virtually all current efforts to improve care for those with chronic illness focus on the early diagnosis and management of the disease (i.e., disease management programs) and tend to ignore the fact that care needs are shaped by the eventual outcome of the illness. The dying have different care needs than those who are sick but stable or likely to improve.

The only program for specialized end-of-life care is hospice. Hospice has shown that care can effectively and efficiently focus on just the final phase of life. Hospice utilizes less costly sites of care and providers from multiple disciplines working in close teams; attends to specific personal, spiritual, and clinical needs; and delivers appropriate medical, nursing, and social supports. Hospice acts both as an

55. See Connors, *supra* note 33, at 1596.

56. See Alzheimer's Ass'n et al., *Measuring Quality of Care at the End of Life: A Statement of Principles*, 45 J. AM. GERIATRICS SOC'Y 526, 526-27 (1997).

insurer and as a provider in that it delivers almost all needed care for a global payment (mostly a set rate per day at home, with other rates for in-patient or continuous nursing attendance). Hospice has set the standard for good end-of-life care through the use of interdisciplinary teams that coordinate care and manage costs, a focus on the patient and family as the unit of care, and reliable and effective service delivery (e.g., 24 hour on-call availability of providers) and state of the art pain and symptom management. The benefit is quite flexible compared to traditional fee-for-service. The average per diem was \$96 per day in routine home care in 1996; and home care accounts for nearly 90% of all days of care.⁵⁷ The program has enjoyed wide approval.⁵⁸

By electing hospice (either through Medicare or private insurance), patients agree to forgo "life prolonging" interventions and, instead, receive comprehensive medical and support services not otherwise available under Medicare or their insurance.⁵⁹ A study examining the effects of hospice on Medicare Part A expenditures during the first three years of the program compared treatment costs between hospice beneficiaries and non-hospice patients who had a diagnosis of malignant cancer during their last seven months of life.⁶⁰ The study findings indicated that Medicare saved \$1.26 for every dollar spent on Part A expenditures.⁶¹ A national evaluation of hospice found that hospice users, compared to weakly matched non-users, were less costly.⁶² For patients in home-based hospice, costs were \$2,221 lower than for "conventional-care patients."⁶³ Care for hospital-based hospice patients was less costly, but only in their last month of life.⁶⁴ However, the final savings over the last year of life totaled \$585.⁶⁵ A follow-up study found that cancer patients who used hos-

57. See *General Information: Hospice Fact Sheet* (visited Jan 21, 1999) <<http://www.nho.org/facts.htm>>.

58. See, e.g., Charles H. Brooks, *Cost Differences Between Hospice and Nonhospice Care: A Comparison of Insurer Payments and Provider Charges*, 12 EVALUATION & HEALTH PROFS. 159 (1989) (study finding hospice home care less costly than non-hospice care); Charles H. Brooks & Kathleen Smyth-Strauch, *Hospice Home Care Cost Savings to Third-Party Insurers*, 22 MED. CARE 691 (1984) (same); CHRIS PERRONE ET AL., AN ANALYSIS OF THE COST SAVINGS OF THE MEDICARE HOSPICE BENEFIT (1995) (same); see also VINCENT MOR ET AL. EDs., THE HOSPICE EXPERIMENT (1988) (explaining the results of the National Hospice Study).

59. See 42 C.F.R. §418.24(b)(3) (1998) (outlining procedure for determining Medicare beneficiary hospice eligibility).

60. David Kidder, *The Effects of Hospice Coverage on Medicare Expenditures*, 27 HEALTH SERVICES RES. 195, 207 (1992).

61. See *id.*

62. See THE HOSPICE EXPERIMENT, *supra* note 58, at 66.

63. See *id.*

64. See *id.*

65. See *id.*

pice cost Medicare, on average, \$2,737 less than unmatched non-hospice users.⁶⁶ But, the apparent cost advantage is somewhat unreliable given the lack of randomization in these studies.

Despite its advantages for patients, Medicare's various restrictions shape and define hospice. The hospice benefit is limited to people who have a "terminal illness with a life expectancy of six months or less."⁶⁷ The relatively predictable, brief final course of cancer is well suited to the prognostic limit and hospice model of care. However, individuals dying with diseases other than cancer generally do not have access to hospice care, mostly because their illnesses do not have clinically evident phases of overt decline at the end-of-life. (See Figure 3). In addition, the requirement that 80% of care be at home⁶⁸ often makes hospice care unavailable for those without family or others who can assist them with medications, hygiene, nutrition, and other personal care services. Thus, hospice ends up serving a very small portion of the dying population. In 1997, hospice provided services to an estimated 495,000 patients.⁶⁹

Moreover, hospice only serves its patients for a short period of time. Large hospice providers report that they now have median lengths of stay of less than two weeks.⁷⁰ Christakis and Escarce found the median survival time after enrollment for Medicare patients in 1990 was only 36 days.⁷¹ Almost 16% of patients died within 7 days and over 28% died within 14 days of enrollment.⁷² Only 15% of Medicare patients enrolled in hospice were alive for six months or more.⁷³ The authors concluded that the majority of hospice patients enter too late to benefit from hospice and indicated that the optimal length of stay for hospice patients is three months.⁷⁴

66. See BARABRA MANARD & CHRISTOPHER PERRONE, *HOSPICE CARE: AN INTRODUCTION AND REVIEW OF THE EVIDENCE* (National Hospice Org., 1994).

67. See 42 C.F.R. §418.3 (1998).

68. See 42 C.F.R. §418.302(f)(1) (1998).

69. See National Hospice Organization, *Hospice Fact Sheet* (updated Summer 1998) <<http://www.nho.org/facts.htm>>; STATISTICAL ABSTRACT, *supra* note 13, at 134 (reporting that hospice served 340,000 dying patients (about 15% of 2,294,000 deaths) in 1994).

70. Interview with Carolyn Cassin, Chief Operating Officer, VistaCare, in Washington, D.C. (June 1998); Interview with David Rehm, Regional Vice President of Operations, VistaCare, in Washington, D.C. (June 1998); Interview with Melanie Merriman, Consultant, Touchstone Consulting, in Washington, D.C. (Aug. 1998).

71. See Nicholas A. Christakis & Jose J. Escarce, *Survival of Medicare Patients after Enrollment in Hospice Programs*, 335 NEW ENG. J. MED. 172, 174 (1996).

72. See *id.*

73. See *id.*

74. See *id.*

Increased utilization of hospice has been retarded by recent audits conducted by the Department of Health and Human Services (DHHS) Office of the Inspector General (OIG) under "Operation Restore Trust," which has alleged improprieties in hospices that enrolled persons who live beyond six months.⁷⁵ The first audit report, issued in late 1996, stated that the hospice investigated had erred in admitting 176 of the 364 patients who were either enrolled for more than 210 days or who had been discharged alive over a 27 month period.⁷⁶ However, those 364 cases represented about 2% of all patients enrolled in the hospice during that period, and the hospice had an overall median length of stay of only 47 days.⁷⁷

One important implication of the OIG's campaign is that the current Medicare hospice benefit does not support a longer length of stay for those dying of cancer and cannot be made to match the course of most of those dying of congestive heart failure and other more unpredictable diseases.⁷⁸ In a recent analysis, the authors applied a number of current expert measures of disease severity of CHF to persons enrolled in the SUPPORT study.⁷⁹ Of the 1300 patients with severe CHF who survived the first hospitalization, three-quarters lived more than six months.⁸⁰ Of the approximately 250 patients who probably would have met criteria for hospice enrollment for severe heart failure, three-quarters were still alive at six months.⁸¹ Thus, the current enrollment criteria can serve to greatly limit hospice access among a very sick population but will do so inequitably, since they are unable to separate the "dying soon" from others with similar needs for services.

According to a 1997 report by the Institute of Medicine (IOM):

[T]he current per diem of \$94.17 for routine home care may discourage the use of certain costly pain medications, even when less expensive drugs fail; late-night nursing visits to deal with medical or emotional crisis; the appropriate application of high-technology equipment (e.g., infusion pumps);

75. See IMPROVING CARE AT THE END OF LIFE, *supra* note 8, at 169 n.11.

76. See *id.*

77. See *id.*

78. See *id.*

79. See BRAD STUART ET AL., THE NATIONAL HOSPICE ORG., MEDICAL GUIDELINES FOR DETERMINING PROGNOSIS IN SELECTED NON-CANCER DISEASES 8 (2d ed. 1996).

80. See *id.* at 2.

81. See Joanne Lynn et al., *Effects of National Hospice Organization Guidelines on Hospice Eligibility and Survival in Congestive Heart Failure*, SGIM (abstract in press, 1998).

and extensive counseling services for particularly distressed patients and families.⁸²

In sum, hospice can offer a unique and beneficial set of services but only for a limited population for a limited length of time. There is no question that hospice can be extremely valuable for individuals with cancer and other highly predictable illnesses. However, to the majority of people in the last phase of life, hospice is not available or appropriate. The combination of the investigations by the OIG, the public's reluctance to "give up" curative treatments and accept hospice, and the limited prognoses eligible for hospice in light of the presently restrictive interpretation of the Medicare hospice benefit, make it clear that dying Americans need another alternative when facing the ends of their lives.

Another noteworthy model of care is the Program of All-inclusive Care for the Elderly, or PACE.⁸³ PACE is a community-based delivery and financing program that integrates acute and long-term care services which go beyond the usual Medicare and Medicaid benefits.⁸⁴ PACE serves nursing home certified frail elderly (55+) in hospitals, physician offices, adult day clinic and home settings from enrollment to death.⁸⁵ PACE is a nationwide demonstration based on the On Lok Senior Health Services begun in 1983 in San Francisco's Chinatown.⁸⁶ PACE programs were developed to test whether the On Lok program could be generalized to other settings and nine sites were granted Medicare and Medicaid waivers to establish PACE programs.⁸⁷ Enrollment is limited to frail elderly certified as eligible for nursing home level care.⁸⁸

Under PACE, comprehensive acute and long-term care services are provided by a single organization through an interdisciplinary team of providers.⁸⁹ Each site offers the same comprehensive array of acute and long-term care services, including adult day care, nursing home care, home care, prescription drugs, and rehabilitation.⁹⁰ The long-term care services are more extensive than those offered in the

82. See IMPROVING CARE AT THE END OF LIFE, *supra* note 8, at 170.

83. See Catherine Eng, *Program of All-inclusive Care for the Elderly (PACE): An Innovative Model of Integrated Geriatric Care and Financing*, 45 J. AM. GERIATRICS SOC'Y 223, 224 (1997).

84. See *id.*

85. See *id.*

86. See *id.*

87. See *id.*

88. See *id.*

89. See *id.* at 226.

90. See *id.* at 225.

traditional Medicare HMOs.⁹¹ PACE is financed through a monthly capitation payment from Medicare and Medicaid.⁹²

PACE sites have had difficulty in enrolling patients (often because eligible persons are reluctant to change physicians) and have had difficulty in recruiting physician and other health professionals.⁹³ Additionally, the target group for PACE is small: nursing home certifiable persons.⁹⁴ The typical PACE enrollee is 80 years old, female, with an average of three limitations in activities of daily living and an average of eight medical conditions.⁹⁵ While PACE appears to have set the standard for excellent, integrated services for the very frail and poor, even more than hospice, its scope of access seems likely to remain quite small for the foreseeable future despite having been made a permanent part of Medicare in 1998.⁹⁶

Another model worthy of discussion is the Social Health Maintenance Organizations, or SHMOs, which extend the idea of a health maintenance organization by including limited long-term care services in their benefit package.⁹⁷ The goal of the SHMO was to enroll an elderly population with a wide range of disability and income levels.⁹⁸ This strategy allowed SHMOs to enroll moderate-income individuals as well as Medicaid eligible and nursing home certified elderly.⁹⁹

The program is voluntary and members pay a monthly premium for services but can disenroll during any month of operation.¹⁰⁰ Members receive all Medicare-covered acute, post acute, and ambulatory services, as well as some supplemental benefits (e.g., prescription drugs, eyeglasses, hearing aids, and non-emergency transportation).¹⁰¹ Those who qualify for long-term care benefits can also re-

91. See *id.* at 230.

92. See *id.* at 224.

93. See *id.* at 226.

94. See *id.* at 224.

95. See MARLEEN L. CLARK ET AL., PACE FACT BOOK, 32, 44, 69 (On Lok, Inc., 2d ed. 1996).

96. See *Legislative Summaries: Summary of Health Related Provisions of P.L. 105-33 Balanced Budget Act*, HEALTH LEGIS. & REG. WKLY., Feb. 4, 1998 available in 1998 WL 10395680.

97. See WALTER N. LEUTZ ET AL., CHANGING HEALTH CARE FOR AN AGING SOCIETY: PLANNING FOR THE SOCIAL HEALTH MAINTENANCE ORGANIZATION (Lexington/Heath, 1985); Charlene Harrington & Robert J. Newcomer, *Social Health Maintenance Organizations' Service Use and Costs*, 12 HEALTH CARE FIN. REV. 37, 37 (1991); Walter N. Leutz et al., *Integrating Acute and Long-term Care*, 13 HEALTH AFFAIRS 59 *passim* (1994).

98. See generally Harrington & Newcomer, *supra* note 97.

99. See Leutz, *Integrating Acute and Long-term Care*, *supra* note 97, at 62.

100. See Charlene Harrington et al., *A Comparison of S/HMO Disenrollees and Continuing Members*, 30 INQUIRY 429, 430 (1993).

101. See Leutz, *Integrating Acute and Long-term Care*, *supra* note 97, at 59-60.

ceive limited nursing home, home care services, homemaker, personal care, and/or adult day care services, provided by the SHMO or under contract to other providers.¹⁰²

Evaluations of the SHMOs identified a number of problems. Enrollment in SHMOs was slow, and evaluators found evidence of favorable selection among enrollees.¹⁰³ Although the SHMO enrollment and service packages were designed to serve a cross-section of functionally able and disabled elderly, the overwhelming majority of enrollees did not have disabilities.¹⁰⁴ According to Manton et al., frail elderly were not proportionately attracted to SHMOs, despite the provision of some long-term care services.¹⁰⁵ In addition, in an attempt to control costs, long-term care services were capped at \$7,500 to \$9,600 per person per year.¹⁰⁶ Thus, SHMOs did not cover extended-stay nursing home care or long-term, intensive home care.

Moreover, almost half of those disenrolling expressed dissatisfaction with medical care (difficulty in getting appropriate tests and treatments, lack of choice of physicians, lack of continuity of doctors, etc.) and complaints about costs (e.g., premiums were too high, benefits dropped).¹⁰⁷ There also was great variation in service utilization across plans and a reduction in service benefits over time.¹⁰⁸ Furthermore, whether acute and long-term care services were actually "integrated" remains an open question.¹⁰⁹

The two principal models of integration of acute and long-term care, the SHMOs and On Lok/PACE, demonstrate that a number of issues still need to be addressed by policy makers and program planners. At one extreme, the SHMO attempts to enroll a broad mix of individuals with and without disabilities and pool their resources to cover the costs of intense care users. Wiener & Skaggs identify two disadvantages to the SHMO approach: modest levels of long-term care benefits and lack of the economies of scale necessary to develop distinct services for disabled members.¹¹⁰

102. *See id.* at 60.

103. *See* Kenneth G. Manton et al., *A Method for Adjusting Capitation Payments to Managed Care Plans Using Multivariate Patterns of Health and Functioning: The Experience of Social/Health Maintenance Organizations*, 32 *MED. CARE* 277, 295 (1994).

104. *See id.*

105. *See id.* at 295.

106. *See* Eng, *supra* note 83, at 230.

107. *See* Harrington et al., *supra* note 100, at 433.

108. *See id.* at 433.

109. *See* JOSHUA M. WIENER & JASON SKAGGS, THE BROOKINGS INST., *CURRENT APPROACHES TO INTEGRATING ACUTE AND LONG-TERM CARE FINANCING AND SERVICES* 38 (1995).

110. *See id.* at 39-40.

At the other extreme, the On Lok/PACE program enrolled a population with severe disabilities and provided comprehensive long-term care services, including nursing home care.¹¹¹ The advantage to this approach is that the needs of this population are the only focus of the program and caregivers from a wide range of disciplines makes it more likely that the needs of the "whole" person were addressed. Nevertheless, these were a small number of very high-cost users of care. In addition, geriatric, interdisciplinary teams, the "heart" of the PACE programs, are difficult to organize and run in the traditional, fragmented service delivery system.¹¹² Kane points out that not only are geriatricians "scarce," the egalitarianism of the team may make it hard for many physicians to accept.¹¹³

Nevertheless, the SHMOs and the On Lok/PACE programs demonstrate important features encouraging for a quality end-of-life care program. However, a variety of other economic, social, and ethical issues within managed care systems could be impediments. Managed care systems, like medical care systems more generally, have not attended to the special needs of aging persons who live with chronic diseases from which they are expected to die.¹¹⁴ Friedman and Kane surveyed the medical directors of 64 HMOs with Medicare risk contracts in 1991 (75% of all Medicare risk contracts) and found that most programs did not have a geriatrician or generalist with additional geriatric training on staff.¹¹⁵ In addition, they found a large majority were not systematically assessing functional status or other important social or health characteristics for the elderly and chronically ill.¹¹⁶ This lack of attention is alarming since Medicare beneficiaries have been enrolling in risk-contract and HMO managed care plans since 1972.¹¹⁷ Approximately 171 risk contracts served 2.8 mil-

111. See Eng, *supra* note 83, at 223-24.

112. See WEINER & SKAGGS, *supra* note 109, at 2.

113. See Robert L. Kane et al., *Qualitative Analysis of the Program of All-inclusive Care for the Elderly (PACE)*, 32 GERONTOLOGIST 771, 780 (1992).

114. See Robert H. Binstock, *Public Policies on Aging in the Twenty-First Century*, 9 STANFORD L. & POL'Y REV. 311, 317 (1998).

115. See Bruce Friedman & Robert L. Kane, *HMO Medical Directors' Perceptions of Geriatric Practice in Medicare HMOs*, 41 J. AM. GERIATRICS SOC'Y 1144, 1146 (1993).

116. See *id.* at 1148.

117. See Friedman & Kane, *supra* note 115, at 1144 ("While the federal government authorized risk contracts with HMOs willing to provide services to Medicare beneficiaries as far back as 1972, only two HMOs entered into such contracts . . .").

lion beneficiaries in 1995 and 10 large HMOs enrolled 44% of all Medicare beneficiaries in 1995.¹¹⁸

Although enrollment by the elderly in managed care plans has been slow and concentrated in a few states, beneficiary enrollment has been expanding rapidly.¹¹⁹ Another issue of concern for a managed care plan has to do with adverse selection.¹²⁰ Managed care organizations that are at full or partial financial risk for plan members may perceive a program which offers integrated care for those nearing the end of life to be financially risky. The special care required by those growing increasingly sick over a lengthy period before they die could be costly, especially if not well organized. The threat of adverse risk selection has created incentives in most managed care plans against investing in care for the terminally ill.¹²¹ Medicare is expanding the risk contracting options available to managed care plans to encourage more plans to enroll greater numbers of beneficiaries.¹²² New risk contract initiatives include Medicare SELECT, which offers a network-based supplemental (Medigap) insurance, risk plans offering point-of-service options,¹²³ and expansion of the SHMO.¹²⁴

The *Balanced Budget Amendments (BBA) of 1997*¹²⁵ mandated innovation and variety in HMO contracting arrangements under Medicare. The new "Part C" of Medicare, called the Medicare+Choice program, allows a wider range of providers to contract with the Health Care Financing Administration (HCFA).¹²⁶ The following options are outlined in the Medicare+Choice provision of the BBA but, as of this

118. See U.S. GENERAL ACCT. OFF., *MEDICARE HMOs: RAPID ENROLLMENT GROWTH CONCENTRATED IN SELECTED STATES 2* (1996) (GAO/HEHS-96-93) (Report to the Honorable John F. Kerry, U.S. Senate) [hereinafter GAO REPORT].

119. See *id.*

120. Adverse selection can be defined as:

The market distortion that arises when subscribers have more knowledge about their individual risks than insurers have or that insurers are allowed to have in their premiums. The effect is that, when insurance purchase is voluntary, a disproportionate number of high-risk subscribers will enroll.

Mark A. Hall, *REFORMING PRIVATE HEALTH INSURANCE* 97 (1994). See also Stanley B. Jones, *Why Not the Best for the Chronically Ill?* 2-3 (The George Washington University Health Insurance Reform Project, 1996) (describing the phenomenon of adverse selection in managed care as the avoidance of enrolling the most costly and needy beneficiaries in a health plan).

121. See *id.* at 2.

122. See *id.* at 4.

123. Under a point of service health plan, members choose how to receive services when the service is needed, with different cost-sharing levels associated with the choice. GAO REPORT, *supra* note 118, at 4 n.8.

124. See *id.* at 4.

125. See P.L. 105-33, 111 Stat. 251 (1997).

126. See Binstock, *supra* note 114, at 317.

writing, only the original fee-for-service Medicare plan and Medicare HMOs are available.¹²⁷

- * ORIGINAL MEDICARE PLAN (FEE-FOR-SERVICE MEDICARE). This option allows beneficiaries to select almost any doctor, hospital or other health provider. Medicare makes its payment for health care services, and the beneficiary pays deductibles and coinsurance and balance billing amounts and may choose to purchase supplemental coverage.
- * HEALTH MAINTENANCE ORGANIZATIONS (HMOs). Beneficiaries must obtain services from a designated network of doctors, hospitals and other health care providers who have agreed to provide care to plan enrollees, usually with little or no out-of-pocket payments.
- * HMOs WITH POINT OF SERVICE (POS) OPTION. When combined with a basic HMO package, the POS allows beneficiaries to selectively go out of network to receive services with higher out-of-pocket payments.
- * PREFERRED PROVIDER ORGANIZATIONS (PPOs). Beneficiaries obtain services from a network of providers that has been set up by the health plan. Beneficiaries can choose to see someone out of network but will pay higher out-of-pocket payments to do so.
- * PROVIDER SPONSORED ORGANIZATIONS (PSOs). PSOs are formed by a group of hospitals and doctors and directly take on financial risk of providing comprehensive health care.
- * MEDICAL SAVINGS ACCOUNTS (MSAs). Medicare pays the premium for the MSA plan and makes a deposit into the Medicare MSA that is established by the beneficiary. These funds pay for services before the deductible is met and for other non-covered services. There are no limits on what providers can charge above the amount paid by the Medicare MSA plan.¹²⁸

The new Medicare+Choice program, which allows a wider range of providers to contract with the Health Care Financing Administration,¹²⁹ while untried, opens the possibility that *MediCaring* teams could contract directly with HCFA or through private physician groups as yet another financing model.

127. See HEALTH CARE FIN. ADMIN., NATIONAL MEDICARE EDUCATION TASK FORCE FACT-SHEET 3 (1998).

128. See *id.* at 3-4.

129. See Binstock, *supra* note 114, at 317.

II. *MEDICARING*¹³⁰: AN ALTERNATIVE FOR A SPECIAL POPULATION

Chronically ill patients in the last phase of life might best be considered a "special population," distinguished by clinical severity (e.g., functional status or cardiac performance status) and their distinct care needs. While some of these patients will have unpredictable courses to death, most will have serious, established, long-term illnesses such as heart failure, dementia, emphysema, and stroke. These patients have traditionally been selected against in managed care marketing and retention¹³¹ and their common needs are not now priorities in routine medical care.¹³²

Reliable and effective care for the dying cannot be targeted just at the "actively dying," as in the hospice paradigm, nor just on the extremely frail, long-term care population, as in the PACE program. Rather, end-of-life care must include *all* people who are affected by serious chronic illness which will cause death, but over a longer, less predictable, period of time than is now provided. Indeed, the problems of those nearing the end of life with an array of chronic illnesses cannot be addressed by the Medicare hospice benefit as it is now structured nor by the mere expansion of the PACE program. Even managed care, which has great potential to serve this population, has incentives to avoid high cost populations. Managed care organizations that are at full or partial financial risk for plan members may perceive a program which offers integrated care for those nearing the end of life to be financially risky.¹³³ The special care required by those growing increasingly sick over a lengthy period before they die could be costly, especially if not well organized. The threat of adverse risk selection has created incentives in most managed care plans against investing in care for the terminally ill.¹³⁴

We need to build a sustainable, accountable system of "usual" care that appropriately serves most seriously ill patients and their families, irrespective of health care delivery setting (e.g., home, nursing home, hospital). Building upon the knowledge and successes of both hospice and PACE, *MediCaring* will be an innovative program of comprehensive and coordinated health care which blends the best of palliative care with the best of medical and disease management, tailored

130. The *MediCaring* projects are planned as a five to six-year series of sequential demonstration programs culminating in a Medicare financed national demonstration designed to reform Medicare.

131. See Jones, *supra* note 120, at 2-3.

132. See *id.* at 3.

133. See *id.* at 4.

134. See *id.* at 2.

to the needs of the seriously chronically ill.¹³⁵ The program focuses on heart and lung disease (i.e., CHF and COPD) patients nearing the end of life (the last 2-3 years).¹³⁶ The *MediCaring*-eligible population will be identified using severity of illness threshold measures specific to major chronic diseases rather than a prognosis definition (as is now the case with hospice).¹³⁷

MediCaring builds on the premise that good care of the dying calls for interdisciplinary approaches to care (e.g., primary care physician, advanced practice nurse, social worker, clergy, etc.), continuity and coordination of care, integration of diverse services delivered in a variety of settings, excellent symptom management, maintenance of function, patient/family counseling and support, attention to spiritual and personal growth issues, and a change in the orientation and culture of providers to provide care shaped by the patient's values and personal situation.¹³⁸

MediCaring would not be a duplication of the hospice or PACE programs.¹³⁹ While comprehensive institutional and community-based care, managed by interdisciplinary teams of health care professionals, marshalling existing resources within the community for social services, and care tailored to the individual's needs are hall-marks of all three programs, *MediCaring* would serve populations not now being served, would extend this care to hospital settings, and would test a financing mechanism (incentives) and range of prices that would allow a systematic program to be instituted in Medicare.¹⁴⁰ For example, PACE membership turns on nursing home certification; that is, only those people with complex medical needs, who require intensive, ongoing care and with substantial functional disability are eligible.¹⁴¹ This is a very different population than that envisioned to be served by *MediCaring*, which would focus on those individuals suffering from advanced CHF or COPD (i.e., both younger and more functionally able than those in PACE but also for whom there are no end-of-life care options).¹⁴² Moreover, *MediCaring* is primarily a pro-

135. See THE CENTER TO IMPROVE CARE OF THE DYING, GEORGE WASHINGTON UNIVERSITY MEDICAL CENTER, *MEDICARING PROGRAM EVALUATION PROJECTS: UPDATE ON PROGRAM DEVELOPMENT ACTIVITIES 1* (visited Dec. 1998) <<http://www.abcd-caring.com/MediCaring.htm>> [hereinafter *MEDI CARING PROGRAM UPDATE*]; see also Skolnick, *supra* note 30, at 1511.

136. See *MEDI CARING PROGRAM UPDATE*, *supra* note 135, at 1.

137. See *id.*

138. See *id.*

139. See *id.*

140. See *id.*

141. See Eng, *supra* note 83, at 223.

142. See *MEDI CARING PROGRAM UPDATE*, *supra* note 135, at 1.

gram financed by *existing* Medicare funds¹⁴³ - generally targeted toward traditional rescue care - and cannot go forward without a restructuring of the payment structure. *MediCaring* is also very different from hospice in that *MediCaring* would use disease severity as the main enrollment criterion and thus, would be able to enroll CHF, COPD, and other diseases, which have inherently unpredictable survival times.¹⁴⁴

MEDICARING SERVICES. Except for hospice services for cancer, there is little data as to how to characterize optimal end-of-life care pathways. End-of-life care has mostly been a by-product of the dominant health care system, arising with no particular attention to disease at death and often with quite variable services: A *MediCaring* program would prioritize services quite differently than conventional care: each patient will have a constant primary care provider (e.g., advanced practice nurse and/or physician), regardless of setting (e.g., hospital, nursing home, hospice, home).¹⁴⁵ Services would include, but not be limited to: comprehensive care management coordination, home and personal care, appropriate emergency medical care, access to 24-hour "urgent" care advice nurse with authority to manage care over the telephone, medical equipment and supplies, personal care, rehabilitation, environmental adaptations, and inpatient respite care.¹⁴⁶

In addition, creative combinations of life-prolonging and "supportive care" services would be available (either at home or in an institutional setting) to replace traditional "rescue" care that may no longer serve the patient or reflect responsible stewardship of resources within the care system.¹⁴⁷ Unlike usual hospice practice, however, no treatment (e.g., intensive care, cardiopulmonary resuscitation) will be barred,¹⁴⁸ and thus patients will not have to explicitly give up access to life-sustaining measures.¹⁴⁹ While services could become as extensive as hospice, if needed, it is expected that most *MediCaring* patients will be less dependent, less symptomatic, and less rapidly changing than the usual hospice (cancer) patient, so services will generally be less intensive and vary over time.¹⁵⁰ *MediCaring* would make it easy to get supportive care, which is now hard to get,

143. *See id.*

144. *See id.*

145. *See* Skolnick, *supra* note 30, at 1512.

146. *See id.*

147. *See id.* (quoting comments of Anne M. Wilkinson speaking before the Innovators in End-of-Life Care National Conference in May 1998).

148. *See id.*

149. *See id.*

150. *See id.* at 1513.

and would make it harder to get ventilators and/or surgery, which now are easy.

Comprehensive care management coordination will also incorporate earlier and more open discussion of advance care planning and Do Not Resuscitate (DNR) orders for chronically ill patients in the last phase of life, leading to more appropriate and patient-centered treatments. Decision-making and management of the patient would rest with the patient and families. Effectively, *MediCaring* creates a discernibly different care program for the seriously chronically ill at the end of life much in the same way that we have created systematic obstetrical care as a distinct care program.

MEDICARING ELIGIBILITY. In contrast to hospice, *MediCaring* eligibility criteria would be based on severity and utilization measures specific to major disease categories, with administratively practical and culturally appropriate thresholds of disease.¹⁵¹ For example, people would qualify when an illness becomes severe enough to shape much of the person's life and is expected to be fatal. Defining the thresholds requires more practical experience, but examples might be people who have:

2 hospitalizations within the last year for CHF/COPD; COPD with continuous oxygen ($pO_2 < 55$ at rest) or CHF with ejection fraction of $< 30\%$, and NYHA class III or IV function on a usual day for CHF.¹⁵²

These guidelines will enable the *MediCaring* population to be much broader than that covered under the traditional hospice program. In addition, the program will not bar access to any particular treatment and therefore should not take on the "toxicity" of the hospice label, which many people resist, in part, because it is perceived to be such a harsh turning away from treatment and such a strong marker for imminent death.¹⁵³ Programs that examine a policy of re-allocating resources from traditional hospital-based rescue care to improved home and community supportive care that more appropriately meet the needs of those facing "life-defining, eventually fatal illnesses" would be of great value and would significantly improve quality.

MEDICARING FINANCING. *MediCaring* aims to provide improved home and community-based palliative and supportive care without in-

151. *See id.*

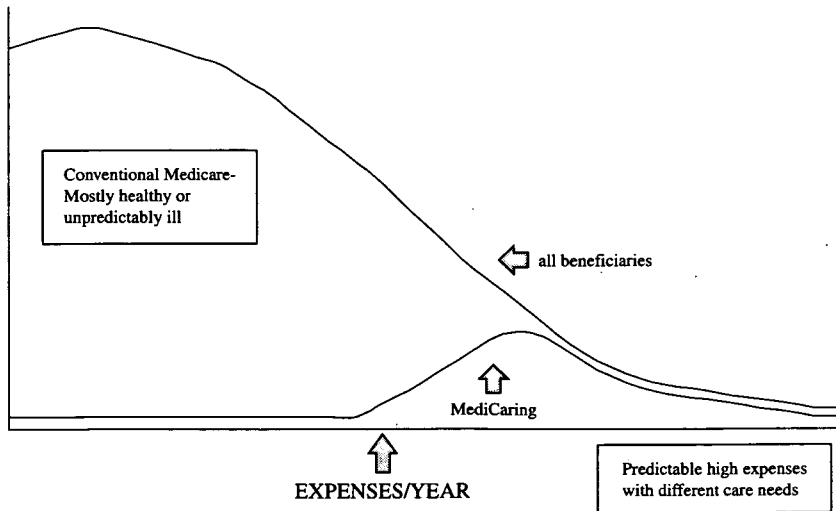
152. *See id.*

153. *See id.* (quoting comments of Anne M. Wilkinson speaking before the Innovators in End-of-Life Care National Conference in May 1998).

creasing average Medicare costs.¹⁵⁴ The potential cost reductions from *MediCaring* will arise mainly from the diminishing use of acute-care interventions that can be prevented, either with aggressive pre-emptive community-based care, by honoring the decisions regarding treatment choices of patients and families, or by the effectiveness of coordination and continuity.¹⁵⁵ Since the *MediCaring* program will serve only “sicker” patients, payment levels to service providers must end up being appropriately adjusted. The proposed demonstration projects will have to include the development of risk-adjusted payments to assure that providers receive sufficient revenues to deliver the comprehensive package of services needed by the average terminally ill person. This is essential in order to encourage improved quality and to attract sufficient numbers of high-cost beneficiaries.

For example, as opposed to “conventional” disease management, all *MediCaring* patients would unambiguously have established diagnoses (which would ensure a low risk of “gaming” the larger Medicare system) and the eligibility criteria could be set so as to accommodate administrative considerations (e.g., the price and services can be set to *match* the populations to be served). Schematically, in any one year, the population expenditures in Medicare look like the following diagram. (See Figure 3).

FIGURE 3
EXPENDITURES IN MEDICARE



154. *See id.*

155. *See id.* (quoting comments of Anne M. Wilkinson speaking before the Innovators in End-of-Life Care National Conference in May 1998).

If *MediCaring* patients were “taken out” of the general insurance pool, two very interesting things would happen. The *MediCaring* population can have a fair rate of capitation or other payments because they have largely predictably high expenses while the non-*MediCaring* population would become a more tractable insurance pool with unpredictable risks of high costs. This kind of program, with tailored services and special payment rates, would work for patients with advanced chronic illness for two reasons. First, the chronically ill population has much less variance than the overall Medicare population and therefore can be identified and then priced at a special rate. Second, the non-chronically ill population has much less variation. High-cost users in the general Medicare population are much more likely to be unpredictable in any one year and, therefore, providers cannot “game” the reimbursement system by selection bias. Providers would then have to compete on value and quality, and not on favorable risk selection. The unpredictable user of services does not generally pose risks of very high costs to the system, and thus could be folded into a general population risk pool that is more equitable for the Medicare program.

MediCaring offers the opportunity to test the important question of fair risk adjustment under Medicare. It is largely *MediCaring* patients who, on the first of any year, can readily be predicted to have high costs that year. It is all too easy now to bias recruitment and retention so as to minimize an organization’s exposure to these risks. If, instead, care provider organizations have to compete on quality and value, the adverse risk selection would theoretically decrease. The participating provider organizations would be responsible for measuring and reporting specific outcomes, including physical and emotional symptoms, advance care planning, aggressive care near death, and patient and family satisfaction. This is essential in setting accountability for quality in the program.

Most financing schemes could support a *MediCaring* program, except traditional fee-for-service. Straightforward fee-for-service, with its separate payments to physicians and hospitals for their services, virtually precludes sustained or widespread excellence in end-of-life care (i.e., routinely establishing multidisciplinary teams, ensuring continuity of care, making promises between patients and providers, and sustaining a care focus upon symptoms, function, and meaningfulness). The hospice model of financing (team capitation and physician fee-for-service), along with the risk-bearing capitation structure of Medicare managed care or PACE, or the salaried budget of the De-

partment of Veterans Affairs (DVA) offer the best opportunities for successful *MediCaring* payment and service delivery.

Each of these reimbursement modes could enable organizations to plan and deliver comprehensive services to defined patient populations, to be accountable for quality and value, and to use centralized resources and flexibility in choice and delivery of services within a capitated or global budget. For example, hospice is financed mainly by a daily capitation.¹⁵⁶ The direct physician payment through Medicare Part B under the hospice benefit, as in traditional fee-for-service medicine, makes hospice reimbursement a very interesting amalgamated payment mechanism.¹⁵⁷ The payment to a team of providers at risk for most patient care, while maintaining separate utilization of physician services, could promote multidisciplinary team management, control of care, and create the potential added role of a primary care physician as an independent patient/family advocate and "whistle-blower" when needed. It also may make passage of a *MediCaring* statute more politically feasible in the long run, since physicians would have less reason to object to such a program because they would still be "included" in the patient's care and patients would be reassured by being able to remain with a long-standing physician. Salaried systems, such as the DVA, offer the advantage of fewer reasons to find the care provider in ethical conflicts of interest with very sick patients. While fee-for-service physicians might risk over-use of interventions and managed care physicians might risk denying services, salaried physicians have much less incentive in either direction.

Financing end-of-life care under a program like *MediCaring* would free care systems to realize system efficiencies, such as utilizing potentially lower cost palliative care services in a variety of lower cost settings (e.g., hospital, nursing home or home) coordinated by lower cost nurses or health professionals (e.g., nurses, nurse practitioners) and to develop innovative programs with more flexibility in service delivery arrangements by utilizing pooled Medicare, Medicaid, and private wealth. In addition, extending a health plan's responsibility to cover the full range of end-of-life care services would encourage plans to control service delivery though more careful deliberation about what types of acute and long-term care services would most benefit the patient, family, and the care system.

156. See MANARD & PERRONE, *supra* note 66, at 14.

157. See *id.* at 14-15.

III. FEDERAL INITIATIVES THAT COULD IMPACT END-OF-LIFE CARE

Recent trends and directives from the federal government, in addition to the changes inherent in the aforementioned Medicare+Choice program, may have a real impact on the plausibility of a *MediCaring* program implementation. The Advance Planning and Compassionate Care Act of 1997, introduced by Senator Rockefeller (D-WV) and Senator Collins (R-ME) and Representative Levin (D-MI), requires the Secretary of Health and Human Services to conduct demonstration projects to develop new and innovative approaches to providing end-of-life care to Medicare beneficiaries who are seriously ill or who suffer from a medical condition likely to be fatal.¹⁵⁸ If legislation like this is passed, *MediCaring* could be a candidate for this kind of federally-mandated demonstration.

Another legislative directive that may affect a possible role for *MediCaring* is the statement of the Bipartisan Medicare Commission to be released in March 1999.¹⁵⁹ The Commission may determine that there is a need for increased funding for demonstrations so that innovative programs can be tried and possibly implemented. There has been a great deal of furor in recent months about the long-term feasibility of the Medicare program¹⁶⁰—Congress may well be looking for ways to use monies in alternative and innovative fashions.

Finally, the assisted suicide debates that have been ubiquitous in media articles, professional forums, and public domains have piqued legislative concern around the end-of-life care debate.¹⁶¹ The Lethal Drug Abuse Prevention Act of 1998, which was introduced but then failed, evidenced an effort to put an end to the legalized practice of assisted suicide but also illustrated Congressional interest in providing

158. See S. 1345 §7, 105th Cong. (1997); H.R. 2999 §7, 105th Cong. (1997).

159. Media Advisory, The National Bipartisan Commission on the Future of Medicare, June 12, 1998 (on file with authors).

160. See Kevin P. Kane, *We're in the Money . . . or Are We?*, ST. LOUIS POST-DISPATCH, Feb. 25, 1999, at B9 (discussing Congress' and President Clinton's proposed budget plans to ensure Medicare solvency for future decades); *Politics & Policy Medicare: Panel Airs Projections as Deadline Looms*, AM. POLITICAL NETWORK, Feb. 23, 1999, at 3 (discussing Medicare Commission's possible proposals and policy experts' predictions of impact on Medicare); *Difficult Work Heats Up*, CONG. DAILY, available in 1999 WL 7532251 (discussing pressure on Congress to address Medicare insolvency).

161. See *Casting a Cold Eye on 'Death with Dignity' Oregon Studies Year One of a Benchmark Law*, U.S. NEWS & WORLD RPT., Mar. 1, 1999, at 56 (discussing impact of Oregon's controversial physician assisted suicide law); Clarence Page, *When the Right-to-Die Advocates Threaten Our Right to Live*, CHI. TRIB., Feb. 24, 1999, at 17 (discussing events of journalist Mike Wallace's lecture at the University of Michigan on the videotaped assisted suicide airing on CBS' *60 Minutes*); Erin Hoover Barnett, *Assisted Suicide Remains a Hot Issue in Legislature*, PORTLAND OREGONIAN, Feb. 7, 1999, at C08.

appropriate comfort care for those in the last phase of life.¹⁶² A system like *MediCaring* might offer a viable alternative for Americans seeking the ability to live as fully as possible with serious chronic illness, and thereby move the focus away from the question of assisted suicide to an answer of improved access to services.

CONCLUSION

We have a vision of a care system that will serve the vast majority of dying persons, in which the usual person coming to the end of their life is comfortable, confident of the care they will receive, and living a meaningful life in care systems that are proud of high value, sustained care. The aim of *MediCaring* is to help providers deliver on that vision by being able to promise dying patients the following:

- patients will be offered the best of medical treatment, aiming to prevent exacerbations, improve function and survival, and ensure comfort;
- patients will never have to endure overwhelming pain, shortness of breath or other symptoms;
- care will be continuous, comprehensive and coordinated;
- the patient and family will be prepared for everything that is likely to happen in the course of the illness;
- wishes of the patient will be sought and respected, and fulfilled whenever possible; and
- as providers we will do all we can to see the patient and their family will have the opportunity to make the best of every day.

There are intriguing and attractive attributes in a model of health care that includes a recognition of impending death, that provides the right services at the right time, and has a financing mechanism that pays a fair price. *MediCaring* would establish the needed protocols, standards for accountability, and an appropriate pathway for most dying individuals. It would create a risk-bearing entity (e.g., the multidisciplinary team) with responsibility and accountability for quality as well as value, and it would provide a mechanism to eliminate the intense pressures on the current system to fill gaps in the current system, either by “stretching” hospice eligibility or overusing home health care.

MediCaring offers unique possibilities for efficiencies in service delivery and efficacy in service composition to its clients. With its multidisciplinary approach, *MediCaring* can deliver on the promises of a good dying, allowing for a better “fit” between client and family needs

162. See S. 2151, 105th Cong. (1997).

and services provided. Moreover, *MediCaring* offers health care providers an opportunity to develop the special expertise in palliative care, case management, and supportive care services needed to appropriately manage a seriously ill population. Under *MediCaring*, allied health professionals, specialists, and supportive services can all be brought together under one management structure to create continuity, quality standards and accountability systems. Thus, the organizational resources needed (e.g., provider feed-back processes, data reporting systems, integrated care delivery and financing, etc.) to ensure the systematic pre-planning of services, effective management of care, continuity across service settings, and measurement of outcomes for quality and accountability could easily be established.

Methods for comparing providers on the basis of quality, not just price, could be implemented, thereby making measurement and improvement part of everyday practice. Consumers would benefit by being able to intelligently select a provider based on clear, objective indicators of quality, pain in the last weeks of life, psychological support provided to family after the death, etc. There is now no equivalent opportunity for accountability to be "built into" conventional medical care.

Finally, controlling the costs of medical care and providing excellent care at the end-of-life will require policymakers, politicians, physicians, and elderly patients themselves to evaluate the costs and benefits of high technology interventions. Demonstrations such as *MediCaring*, which examine a policy of reallocating resources from traditional hospital-based "rescue" care to improved home and community supportive care that more appropriately meets the needs of those facing "life-defining, eventually fatal illnesses," will be of great value. Thus, projects to learn how to implement a good care system for dying Medicare patients are extremely important. The *MediCaring* projects are planned as a five to six-year series of sequential demonstration programs culminating in a Medicare financed national demonstration designed to reform Medicare. The evaluation components of *MediCaring* will specifically assess the cost-effectiveness of the program, the clinical thresholds used to define "terminal" illnesses, the desirability of the services to beneficiaries, and the extent to which quality of care has been improved including changes in advance care planning, aggressive care near death, and patient and family satisfaction.

There is no question that the time is ripe for the implementation of a *MediCaring*-like program and for the aforementioned promises to become reality for all patients and families. The aging of the baby

boomers paired with the recent drastic improvements in medical technology mean that all of us—whether for ourselves or for aging parents—need to be able to rely on a health care system that can meet the variable needs of the seriously ill, even if those needs span a course of years. In the debate over physician-assisted suicide, people talk about the right to a “choice” of having a provider assist in suicide. This isn’t a true “choice” unless there exists an option of a health care system that can adequately care for dying people. *MediCaring* or similar alternatives could provide that option. And, regardless of one’s position in the controversial physician-assisted suicide debate, we can all agree that options are what we want when facing the ends of our lives.