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THE HOSPICE MOVEMENT: A RENEWED VIEW OF THE DEATH PROCESS*

INTRODUCTION

Modern medical technology and its increasing ability to prolong life has caused the Western world's attitudes toward death to come full circle. Two thousand years ago, Western man prepared for death in a very personal manner signified by a public ritual, symbolic of the acknowledgement of death as the universal destiny.¹ "During the Middle Ages, however, death became a personalized test or challenge - how one performed in the process of dying was viewed as predicting how one would spend eternity."²

The birth and advance of modern medical technology during the mid-twentieth century has come to represent the ultimate avoidance of death. As Rep. Stewart McKinney noted when he addressed Congress regarding the care of the terminally ill in 1978, patients were tucked away in hospitals where "life" prolonging technologies were used, where patient individuality and autonomy disappeared, and where the moment of death was calculated based more on the functioning of a machine than on the individual's functioning as a person.³

Today, these advancing medical technologies, including artificial organ transplantation, continue to offer new and expanded methods to prolong life. Yet, these same methods are being tempered by a more humane and sensitive approach in the treatment of the terminally ill patient,⁴ culminating in a revival of the concept of "hospice."⁵ Hospice represents "an approach to

* The author wishes to acknowledge the assistance and cooperation of Ms. Anne Towne, Executive Director, Hospice Care of the District of Columbia, in providing information for the case study portion of this comment.

1. 124 CONG. REC. 13,552 (1983) (statement of Rep. S. McKinney).

2. *Id.* at 13,553.

3. *Id.*

4. For a complete discussion of the dying patient's perception of death, see E. KUBLER-ROSS, *ON DEATH AND DYING* (1969).

5. Hospice is:

a medically-directed, nurse coordinated program providing a continuing program of home and patient care for the terminally ill patient and his family, employing an interdisciplinary team acting under the direction of an autonomous hospice administration. The program provides palliative and supportive care to meet the special needs arising out of the physical, emotional, social and economic stresses which are experienced in the final stages of illness and during dying and bereavement. This care is available 24 hours a day, seven days a week and is provided on the basis of need

treatment that recognizes that the impending death of an individual warrants a change in focus from curative care to palliative care."⁶

Because cancer is one of the leading overall causes of death in the U.S. - second only to heart disease⁷ - the renewed focus on hospice care is destined to impact the traditional health care delivery system. As the hospice concept grows in acceptance, individuals in the terminal stages of cancer will opt for the holistic treatment of hospice rather than the fragmented and often impersonal treatment offered the dying in the acute care hospital setting. Furthermore, the ever increasing spread of AIDS and its devastating and debilitating course as well as the emphasis on treatment of patients with Alzheimer's disease⁸ herald an expanding role for the hospice philosophy.

This Comment explores the revitalization of the hospice concept and its potential impact on the care of the terminally ill. To do so, the historical development of the hospice concept is traced, followed by a discussion of the modern hospice concept and the various structural models currently available for delivering hospice care. Additionally, this Comment reviews the growth of the hospice concept in the reimbursement arena, from a demonstration project of the Health Care Financing Administration ("HCFA") to a permanent reimbursable provision of the Medicare⁹ program. The focus of the Comment then shifts to an analysis of the cost effectiveness of hospice treatment, followed by brief mention of some of the more relevant legal and ethical problems incurred in the course of hospice treatment. A hospice located in Washington, D.C. is used to illustrate the melding of the various hospice elements. Finally, this Comment concludes with suggestions for the expansion of hospice care and additional actions to be taken to assure continued growth of the hospice philosophy.

DEVELOPMENT OF THE HOSPICE CONCEPT

Middle Ages through Modern Day

The word "hospice"¹⁰ has historically been associated with the idea of an

regardless of ability to pay. Such care of necessity requires careful record keeping for coordination of patient care as well as for use in education and research.

Flexner, *The Hospice Movement in North America*, 73 SO. MED. J. 631 (1980) (citing the National Hospice Organization).

6. 48 Fed. Reg. 56,009 (1983).

7. Deaths per 100,000 population for 1984: Heart disease 324.4; cancer 191.6. A. TOWNE, SPECIAL REPORT TO THE BOARD OF DIRECTORS ON HOSPICE CARE OF THE DISTRICT OF COLUMBIA, at 3 (1986) (citing the D.C. Department of Human Services).

8. Volicer, Rheume, Brown, Fabiszewski & Brady, *Hospice Approach to the Treatment of Patients with Advanced Dementia of the Alzheimer Type*, 25 J. A.M.A. 2210 (1986).

9. 42 U.S.C. § 1395ww (1985).

10. The term hospice derives from the Latin *hospitium* (hospitality) signifying an inn and

inn maintained by a religious order for the benefit of the weary traveler.¹¹ In the Middle Ages, hospices were often located at hazardous crossroads¹² in order to offer food and shelter to travelers on pilgrimages to the Holy Land.¹³ Gradually, these rest stations evolved into infirmaries providing shelter and relief for minor ailments.¹⁴ Interestingly, however, there was no real curative aspect to any of the treatment offered.¹⁵

One of the first such recorded shelters was established by the Order of the Knights of St. John of Jerusalem to care for soldiers who fell ill en route to the Holy Land during the first Crusade in the eleventh century.¹⁶ A more well known example is the Great St. Bernard Hospice in the Swiss Alps, where the Augustine monks and their famous St. Bernard dogs served many snowbound travelers.¹⁷ In contrast to the modern hospice concept, the early hospice development had nothing to do with the idea of death; rather, the focus was on giving shelter to pilgrims and enabling them to continue their journey.¹⁸

The focus began to shift in the latter part of the seventeenth century when Vincent de Paul and the Sisters of Charity established hospices in France to care for the poor and sick.¹⁹ Subsequently, the late 1800's witnessed the founding of a shelter by the Sisters of Charity at Harold's Cross in Dublin, Ireland designed specifically to care for the incurably ill.²⁰ This religious order continued to expand its hospice facilities and, in 1906, St. Joseph's Hospice was opened in London, England.²¹ It was at St. Joseph's Hospice and St. Luke's Hospice during the 1950's and 1960's that Dr. Cicely Saunders²² gained exposure to and developed her personal philosophy of the con-

the French *hospes* for stranger or guest. WEBSTER'S NEW COLLEGIATE DICTIONARY 400 (9th ed. 1986). For a complete tracing of the derivation of the term "hospice" by Dr. Charles Talbot, medievalist of the Wellcome Institute for the History of Medicine, London, England, see, Goldin, *A Protohospice at the Turn of the Century: St. Luke's House, London from 1893 to 1921*, 36 J. HIST. MED. 386 (1981).

11. WEBSTER'S NEW COLLEGIATE DICTIONARY 400 (9th ed. 1986).

12. S. STODDARD, *THE HOSPICE MOVEMENT - A BETTER WAY OF CARING FOR THE DYING* 7 (1978).

13. Goldin, *supra* note 10, at 387.

14. K. COHEN, *HOSPICE - A PRESCRIPTION FOR TERMINAL CARE* 17 (1979).

15. *Id.*

16. Goldin, *supra* note 10, at 388.

17. COHEN, *supra* note 14, at 17.

18. Dr. Talbot cautions that the early hospices did not deal with death and notes "... Helping them [pilgrims] toward the shrine had nothing to do with helping them toward heaven." Goldin, *supra* note 10, at 389.

19. STODDARD, *supra* note 12, at 64.

20. *Id.* at 65.

21. *Id.* at 66.

22. Dr. Saunders is the Medical Director of St. Christopher's Hospice and is considered by many to be responsible for the revitalization of the hospice movement and the upsurge in

temporary hospice which culminated in the opening of St. Christopher's Hospice,²³ regarded by many as "the prototype of terminal care."²⁴

St. Christopher's Hospice, a fifty-four bed facility, opened near London, England in 1967.²⁵ It receives two-thirds of its funding from the National Health Service²⁶ with the remainder coming from private sources.²⁷ This facility receives approximately 1,500 inquiries a year and actually accepts between 500 to 600 patients annually, using specific criteria to select those patients who will benefit most from available services.²⁸ The underlying philosophy practiced at St. Christopher's is that total care of the dying refers not only to the medical management of symptoms, but, additionally, to the concept that anything producing distress or pain for the dying patient or the family is a matter of concern for the hospice.²⁹

The staff at St. Christopher's is oriented toward meeting the special needs of the terminally ill patient. Paramount among these needs are pain alleviation and control of the symptoms of the individual's disease.³⁰ In order to achieve these goals, Dr. Saunders has placed great emphasis on a proper atmosphere and a willing, able and compassionate staff.³¹ In addition to in-patient services, St. Christopher's also provides an outpatient clinic and a

the humane medical treatment and management of the terminally ill. Dr. Saunders' philosophy of care for the terminally ill may best be summarized by the following quote: "You matter because you are you. You matter to the last moment of your life, and we will do all we can not only to help you die peacefully, but also to live until you die." *Id.* at 91.

23. St. Christopher's Hospice is located in Sydenham, England, southeast of London. P. DUBOIS, *THE HOSPICE WAY OF DEATH* 69 (1980).

24. *Id.*

25. *Id.*

26. For a discussion of the National Health Services see Parkin, *Public Law and the Provision of Health Care*, 7 *URB. L. & POL'Y* 101 (1985).

27. St. Christopher's was officially established outside of the National Health Service. *Id.* at 80. See also *For The Terminally Ill, A Hospital That Cares*, *MED. WORLD NEWS*, July 1974, at 46 [hereinafter *A Hospital That Cares*].

28. The Admissions Committee considers the following major criteria in selecting appropriate patients: (1) medical history, (2) expected length of survival, (3) whether the family can benefit from hospice support, and (4) whether the hospice can help the patient with specific unresolved problems or symptoms. DUBOIS, *supra* note 23, at 70. Other considerations include whether the family lives close enough to be able to visit easily and what the referring hospital's "reputation" is for terminal care. *Id.* at 79.

Interestingly, St. Christopher's also cares for several chronically ill patients, particularly those with motor neuron diseases. Several elderly but relatively well patients also live at the facility. This is done in an effort to avoid being labeled a "death house," as well as to offer the staff some relief from the very intense mental and physical care required by the terminally ill. *A Hospital That Cares*, *supra* note 27, at 46.

29. Dubois, *supra* note 23, at 74.

30. *A Hospital That Cares*, *supra* note 27, at 46.

31. *Id.*

home care program.³²

As a result of the great success experienced with the British hospices, the concept gradually spread across the Atlantic. A group of individuals connected with Yale-New Haven Hospital and led by Florence Wald³³ spent a great deal of time living and studying at St. Christopher's, the prototype hospice. Their efforts culminated in the founding, in 1971, of Hospice, Inc., later renamed the Connecticut Hospice, the first American hospice.³⁴ Originally established as a home care program, Hospice, Inc. constructed a forty-four bed inpatient facility in 1979 which was designed to house a day care program and provide outpatient services.³⁵

Following the establishment of Hospice, Inc., the American hospice movement received encouragement and funding from the National Cancer Institute ("NCI")³⁶. Initially, focus in the United States was placed primarily on free-standing inpatient hospice facilities. This contrasted with hospice development in Canada which focused on separate units located within a general hospital.³⁷ Gradually, however, the United States system began to examine home care programs for economic reasons. Today, the National Hospice Organization reports that there are approximately 1,400 hospice programs in the United States, representing essentially four basic models.³⁸

Current Models of Delivering Care

There are four basic models used in the United States for the delivery of hospice services. They include: (1) home care programs, (2) free-standing inpatient facilities, (3) separate unit within a hospital or skilled nursing facil-

32. *Id.* Additional aspects of the hospice philosophy developed by Dr. Saunders at St. Christopher's will be addressed throughout the comment.

33. Florence Wald was a nurse at Yale-New Haven Hospital who cared for dying patients and authored a study on the terminally ill in the 1960s. DUBOIS, *supra* note 23, at 86.

34. *Id.* at 85.

35. Osterweis, *The US Hospice Movement: Issues in Development* 69 AM. J. PUB. HEALTH 493 (1979).

36. NCI contracted for three inpatient demonstration projects in the late 1970s. These contracts were awarded to: Kaiser-Permanente, a health maintenance organization in Los Angeles; Hillhaven Hospice of Tucson, Arizona, which provides home care, day care, inpatient and bereavement services; and Riverside Hospital, which renovated a house in which to provide inpatient hospice care. The Arizona hospice is physically and functionally separate from the skilled nursing facility and residential facility located on the same ground, with the exception of a contractual arrangement for certain support services, (e.g., dietary and laundry). Osterweis, *supra* note 35.

37. The Palliative Care Unit of Royal Victoria Hospital began operation in 1975 with 12-14 beds. In addition to providing inpatient care, services are also offered through a home care program as well as a consulting service within the hospital. *Id.*

38. Interview with Ms. Anne Towne, Executive Director, Hospice Care of the District of Columbia, in Washington, D.C. (October 17, 1986) [hereinafter Towne Interview].

ity and, (4) an interdisciplinary team which operates within a general hospital and sees patients scattered throughout the facility.³⁹

Home care hospice programs, or "hospices without walls"⁴⁰ provide a core of services to the patient and his family in a home setting. This type of program seems particularly appropriate for rendering care to the terminally ill since most of these patients express a preference to die at home.⁴¹ Home care hospice programs enable the family to keep a dying patient at home by providing 24-hour, 7-day-a-week medical and nursing care, instruction in patient care techniques for family members, and emotional support and bereavement counseling.⁴² Some other services provided by home care programs include arranging for aides to come into the home to assist with routine daily care or to stay with a patient to allow family members some cherished time alone. Also, volunteers can be assigned to do shopping and run errands. It is predicted that the home care model will continue to grow because of its inherent cost effectiveness realized through the use of volunteers and less costly methods of treatment.⁴³ Frequently, the responsibility of caring for a terminally ill relative on a daily basis can become overwhelming. In this instance, the home care hospice program can lend additional support by coordinating a temporary placement in a free-standing inpatient hospice or hospital-based facility which provides respite care.⁴⁴

The second hospice model, the free-standing inpatient hospice facility, is set up so as to either be completely autonomous with its own administration or directly affiliated with a hospital or skilled nursing facility.⁴⁵ The former model is preferable due to the autonomy factor and the freedom from the institutional politics of an affiliated relationship.⁴⁶ However, the growth of the free-standing hospice is unlikely due to the scarcity of capital construc-

39. The variations in delivery mechanisms serve to reinforce the fact that hospice is not an institution or a place, but rather a philosophy. See Cohen, *supra* note 14, at 68.

40. Reiss, *Hospice Care - A Federal Role?* (Cong. Res. Service 1982).

41. Cohen, *supra* note 14, at 68.

42. Reiss, *supra* note 40.

43. Cohen, *supra* note 14, at 69. Delivery of home hospice services results in a reduction of the use of ancillary services so often utilized in the inpatient setting. Although home hospice care may be labor intensive, savings accrue due to the use of unpaid family members and volunteers. A further benefit of the home care model is the absence of capital requirements for constructing and maintaining treatment facilities. See Mor & Kidder, *Cost Savings in Hospice: Final Results of the National Hospice Study* 20 HEALTH SERVICES RESEARCH 407 (1985).

44. COHEN, *supra* note 14, at 8.

45. Reiss, *supra* note 40, at 8.

46. In support of the growth of the totally free-standing facility, Lawrence Burke of the National Cancer Institute has noted that "it would more than compromise and complicate the (hospice) program to have it initiated within a general hospital." COHEN, *supra* note 14, at 69. This sentiment most likely springs from the essential difference between hospital-oriented and hospice-oriented care - the former is curative, the latter palliative. Combining the two under

tion funds and the available excess bed capacity in traditional health care facilities.⁴⁷

The third model, separate hospice units located within existing health care facilities may present a feasible solution to the current problem of excess capacity in the mainstream health care system.⁴⁸ Such units still permit a certain degree of program autonomy despite their connection with the health-care facility. Moreover, units specifically allocated for hospice patients foster the compassionate atmosphere associated with the hospice philosophy. However, hospices located within an existing facility face the possibility of being labelled "death wards."⁴⁹ Coordinated and purposeful efforts must be undertaken to avoid such negative connotations while promoting the true essence of the hospice concept - quality life for as long as there is life.

The fourth innovative approach for delivering hospice services within existing traditional facilities is the use of an interdisciplinary team which provides supportive, palliative care to dying patients.⁵⁰ Additionally, members of such a team may act as "ombudsmen"⁵¹ for the terminally ill and assist regular hospital staff in dealing supportively with hospice patients and their families.⁵² Use of the interdisciplinary, hospital-based team offers the terminally ill patient access to the basic hospice concepts when resources have not been committed to a separate hospice unit. The major advantage of this approach is the humanization of the dying process in the traditional acute care setting. However, due to the palliative-curative distinction, it may prove difficult for such an interdisciplinary team to integrate with the traditional care approach.

Although each of the purported hospice models discussed share a basic conceptual approach, they differ in terms of staffing, service components,

one organizational structure portends of areas of unsolvable conflict regarding access to the ever-shrinking budgeted health care dollar. *See id.*

47. Osterweis, *supra* note 35, at 494. Additionally, Dr. Balfour Mount of the Royal Victoria Hospital has questioned the economic feasibility of free-standing hospices. "Analysis of the economics of maintaining such institutions . . . suggests that society cannot afford to support an adequate number to meet the need." *See Cohen, supra* note 14, at 69.

48. In addition to hospitals, nursing homes have been considered as alternate sites for providing hospice services. However, excess nursing home beds are in short supply. Many hospice advocates question the appropriateness of nursing home placement due to the predominantly custodial nature of the care provided. The hospice philosophy is holistic in approach, not custodial. *See Osterweis, supra* note 35, at 495.

49. *See COHEN, supra* note 14, at 69.

50. Reiss, *supra* note 40, at 8.

51. An Ombudsman is "one that investigates reported complaints, reports findings, and helps to achieve equitable settlements." WEBSTER'S NEW COLLEGIATE DICTIONARY 823 (9th ed. 1986).

52. Reiss, *supra* note 40, at 8.

reimbursement arrangements and physical setting.⁵³ All, however, share an element of commonality: by providing a hospice alternative, these programs enhance the efficiency of the mainstream health care system.⁵⁴ By removing patients requiring a lower level of care from the acute setting, these various models encourage and support appropriateness in established treatment modalities.⁵⁵

Hospice: The Essential Criteria

A hospice is distinguishable from the traditional health care system because of certain basic principles utilized in the provision of services to the terminally ill. First, the patient and his family, not just the patient, are considered the unit of care. Second, a multi-disciplinary team is used to assess the physical, psychological, and spiritual needs of the patient and family, to develop an overall plan of care, and to provide coordinated care. Third, pain and collateral symptoms associated with the terminal illness and its previous treatment are controlled, but no heroic efforts are made to cure the patient. Finally, bereavement follow-up is provided to the family to overcome their emotional suffering.⁵⁶

Underlying all hospice services is the basic philosophy of providing "an environment in which to die, but not of actively prolonging life or accelerating death."⁵⁷ Hospice attempts to ease individuals, patients and families alike, into the "realization and conscious acceptance of dying and death as a part of being born and part of the struggle of life."⁵⁸ The concept that death is not to be considered a failure but, rather, the ending to a full life cycle⁵⁹ is evidenced by the focus on care for the terminally ill patient rather than treatment of the patient's disease.⁶⁰ In caring for the terminally ill patient, the hospice movement seeks to meet four major needs - three related to the pa-

53. Osterweis, *supra* note 35, at 494.

54. "[T]he existence of a hospice alternative allows acute care beds to be used for acute care patients." *Id.* at 496.

55. *Id.*

56. U.S. General Accounting Office, *HOSPICE CARE - A GROWING CONCERN IN THE UNITED STATES* 7 (1979). Additional elements considered necessary for the ideal hospice program include: service availability 24 hours a day, seven days a week; home care service in collaboration with inpatient facilities; physician-directed services; central administration and coordination of services; use of volunteers as an integral part of the team; acceptance to the program based on health needs, not on ability to pay. See COHEN, *supra* note 14, at 71.

57. COHEN, *supra* note 14, at 2 (citing Hill Haven Hospice Medical Newsletter).

58. STODDARD, *supra* note 12, at 22 (quoting Leonard Ligner, M.D.).

59. In a workshop on Hospice in Los Angeles, Douglas McKell noted, "It is the *dis-ease* of dying that hospice seeks to eliminate through the control of symptoms." COHEN, *supra* note 14, at 2.

60. Anspaugh, *The Hospice: Advocate for the Dying*, 9 HEALTH EDUC. 3 (1978).

tient and one to the family. The specific needs of the patient are: "(1) to control pain effectively; (2) to be loved and to alleviate loneliness; and (3) to retain dignity or feelings of self-worth and maintain control of as many aspects of one's life as possible."⁶¹ Concomitant with these are the need of the family to be supportive and to adapt to their inevitable loss.⁶²

As discussed previously, pain relief is central to the hospice mode of care. The chronic, intractable pain of many terminal illnesses,⁶³ particularly cancer, can leave an individual physically drained, emotionally spent and thoroughly depressed.⁶⁴ Dr. Cicely Saunders of St. Christopher's Hospice has long advocated the vital role of pain relief in the care of the terminal patient and is a pioneer in the use of polypharmacy as part of the palliative care provided such patients.⁶⁵ Providing drugs to patients on a regular basis⁶⁶ has proven to be successful in preventing pain from occurring instead of relieving it once it has occurred.⁶⁷ At the same time, it offers optimum relief without oversedation.

Accreditation/Licensure: A Move Toward Quality of Care

Pain relief is only one of the many treatment aspects which contribute to the overall quality of care rendered in the hospice setting. Some measure of quality of care is important not only to safeguard the well being of the pa-

61. *Id.*

62. *Id.*

63. Studies have revealed that of those who die of all forms of malignant disease, some 50 percent are unlikely to experience pain at all. Another 10 percent may experience mild pain only. The remaining 40 percent will need help for severe or intractable pain. Saunders, *Control of Pain in Terminal Cancer*, 75 NURSING TIMES 13 (1979).

64. In particular, cancer pain is of a constant and persistent nature. "Such chronic pain can be characterized as a vicious circle with no set time limit." COHEN, *supra* note 14, at 92 (citing Mount, *Use of the Brompton Mixture in Treating the Chronic Pain of Malignant Disease*, 115 CAN. MED. A. J. 122 (1976)).

65. In this context, polypharmacy is the use of several medications in a single situation aimed at keeping the patient free of pain yet in a functionally alert state. A primary example of an effective polypharmacologic approach is the Brompton's Mixture originally formulated at Brompton's Chest Hospital in England. The original British formula typically contained: Diamorphine HCl (heroin) (5-10 mg), Cocaine (10 mg), alcohol (90 percent), Syrup (2.5 ml.); Chloroform water to 10 ml. with phenothiazine to potentiate the effect of the diamorphine and also to act as an antiemetic and tranquilizer. In the U.S., morphine is used in lieu of heroin, as heroin use is illegal. This mixture is most effective when given on a continuous every four hour schedule. See STODDARD, *supra* note 12, at 47, 183.

66. This "preventive schedule" is in contrast to the "as needed" or "prn" schedule commonly used by traditional inpatient facilities. Interestingly, a study at Royal Victoria Hospital in Montreal showed that patients in the hospice unit obtained significantly greater pain relief from the same dose of medication than did patients in the hospital's general medical wards. Reiss, *supra* note 40, at 9.

67. *A Hospital That Cares*, *supra* note 27, at 46.

tient but is also required by many third party payers in order to secure reimbursement. It is generally agreed that "quality" is a somewhat nebulous term and an extremely difficult concept to define and measure. In the traditional health care delivery system, quality is measured through the use of specific standards for the management, organization and performance of participating health care providers.⁶⁸ To this end, the National Hospice Organization ("NHO") and the Joint Commission on Accreditation of Healthcare Organizations ("JCAHO") have separately undertaken to formulate standards of hospice care for evaluating existing or new programs offering hospice services.⁶⁹ Additionally, various state legislatures have addressed the issue of quality hospice care by enacting legislation containing specific licensure requirements and including hospices under the state certificate of need ("CON") program for purposes of health planning.⁷⁰ Additionally, after much opposition, the hospice concept has finally been accepted at the federal level.

68. Reiss, *supra* note 40, at 28.

69. An initial grant from the Kellogg Foundation in 1981 enabled the Joint Commission to study hospice care in the U.S. and to develop standards and a self-assessment survey process. The Joint Commission standards became effective in January, 1984 and a voluntary accreditation program for hospices was initiated. JOINT COMMISSION ON ACCREDITATION OF HOSPITALS, HOSPICE STANDARDS MANUAL (1983) [hereinafter JCAH MANUAL].

70. As of January, 1987, the National Hospice Organization reported that the following states cover hospice care under their licensure laws: ARK. STAT. ANN. § 5-911.6 (Supp. 1985); COLO. REV. STAT. § 25-3-101 (Supp. 1986); CONN. STAT. ANN. §§ 19a-490 to -503 (West Supp. 1986); FLA. STAT. ANN. § 400.606 (West 1986); GA. CODE ANN. § 31 7-174 (1985); ILL. ANN. STAT. ch. 111/2, para. 6101 *et. seq.* (Smith-Hurd Supp. 1987); IND. CODE ANN. §§ 16-10-6-1 to -18 (Burns Supp. 1986); IOWA CODE ANN. § 135.90 (West Supp. 1987); KY. REV. STAT. ANN. §§ 216B.010 *et. seq.* (Michie/Bobbs-Merril Supp. 1986); MASS. GEN. LAWS ANN. ch. 111, § 57D (West Supp. 1986); MICH. COMP. LAWS ANN. § 333.21411 (West Supp. 1987); MINN. STAT. ANN. §§ 144.50 to .56 (West Supp. 1987); NEV. REV. STAT. §§ 449.0115, 449.030 (1986); N.M. STAT. ANN. §§ 24-1-1 to -5 (1986); N.Y. PUB. HEALTH LAW §§ 4000 - 4010 (Consol. 1985); N.C. GEN. STAT. § 131E-200 -207 (1986); N.D. CENT. CODE § 23-17.4-02 (Supp. 1987); R.I. GEN. LAWS §§ 23-17-2 *et. seq.* (1985); S.C. CODE ANN. §§ 44-71-10 *et. seq.* (Law. Co-op. 1985); W. VA. CODE § 16-5I-2 (Supp. 1987). Additionally, Ariz., Cal., Md., Neb., Ohio, Okla., and Vt. have plans to include hospices in their state licensure laws.

According to the National Hospice Organization, thirteen states plus the District of Columbia cover hospice programs under their certificate of need (CON) laws. These include: ARK. STAT. ANN. § 5-911.9 (Supp. 1985); D.C. CODE ANN. §§ 32-301 to -309 (Supp. 1986); FLA. STAT. ANN. § 381.494 (West 1986); HAWAII REV. STAT. § 323D-43 (1985); KY. REV. STAT. § 216B.020 (Michie/Bobbs-Merrill Supp. 1986); MD. HEALTH-GEN. CODE ANN. § 19-115 (Supp. 1986); MASS. GEN. LAWS ANN. ch. 111, § 25C (West 1984); MICH. COMP. LAWS ANN. §§ 333.2101 *et. seq.* (West Supp. 1987); NEV. REV. STAT. § 439A.100 (1986); N.Y. PUB. HEALTH LAW § 4006 (Consol. 1985); N.C. GEN. STAT. § 131E-175 to -191 (1986); N.D. CENT. CODE § 23-17.2-01 to -15 (Supp. 1987); R.I. GEN. LAWS §§ 23-15-2 *et. seq.* (1985); WASH. REV. CODE ANN. § 70.126.001 to .050 (1987). See NHO, Hospice News, Status of Statutes (1987).

EVOLUTION OF HOSPICE AS A MEDICARE BENEFIT

The Road to Federal Acceptance

Federal acceptance of the hospice concept began in the early 1970's with several governmental agencies funding a variety of demonstration projects related to hospice care.⁷¹ A Hospice Task Force was organized in 1978, at the request of then Secretary of Health, Education and Welfare ("HEW") Joseph Califano, "to examine the status of the hospice movement in the United States, the effect of current government policies, statutes and regulations on hospices, and the appropriate role which the Federal Government might play in hospice development."⁷² The final Task Force report was favorable to hospice care but failed to define a specific federal role in fostering its development.⁷³

Perhaps the most significant government study was the Health Care Financing Administration's ("HCFA") two year demonstration project implemented in 1980. The study focused on cost utilization and quality issues related to twenty-six specific hospice organizations across the country.⁷⁴ Data gathered from this project have been fundamental in effecting changes and improvements in Medicaid⁷⁵ /Medicare hospice reimbursement. In 1981, the JCAHO undertook an eighteen month project to develop quality standards and a model accreditation program for hospice services.⁷⁶

Following the several demonstration projects noted above, legislative action accelerated in the early 1980's,⁷⁷ culminating in September, 1982 with the signing of the Tax Equity and Fiscal Responsibility Act of 1982

71. See Osterweis, *supra* note 35. For example, in 1979 the Administration on Aging (AOA) sponsored several projects geared toward determining how hospice services fit into the traditional system of care for the elderly. SUBCOMM. ON HEALTH OF THE COMM. ON WAYS AND MEANS, BACKGROUND MATERIALS ON MEDICARE HOSPICE BENEFIT, Doc. No., 98th Cong., 1st Sess. (1983) [hereinafter SUBCOMM. ON HEALTH]. See also Reiss, *supra* note 40, at 19-20.

72. SUBCOMM. ON HEALTH, *supra* note 70, at 3.

73. The final report recognized that "the hospice movement as a concept for caring for the terminally ill and their families is a viable concept and one which holds out a means of providing more humane care for Americans dying of terminal illness while possibly reducing costs . . . As such it is the proper subject of Federal support." *Id.*

74. The demonstration sites included eleven hospital-based programs, eleven home health hospices, and four free-standing facilities. All were granted waivers from the then current Medicare/Medicaid reimbursement requirements which did not cover hospice services. Reiss, *supra* note 40, at 19.

75. Title XIX, 42 U.S.C. § 1396 *et. seq.* (1985).

76. See JCAH MANUAL, *supra* note 69.

77. Several preliminary bills were introduced in the House and Senate by Rep. Leon Panetta and Sen. Robert Dole to provide coverage for hospice care under Part A of Medicare. See SUBCOMM. ON HEALTH, *supra* note 71, at 17.

("TEFRA").⁷⁸ TEFRA contained the first Medicare hospice care provisions.⁷⁹ Subsequent to the passage of this legislation, HCFA published the final rules and regulations in 1983.⁸⁰

The proposed regulations for Medicare hospice benefits addressed several key issues and, at the same time, presented numerous obstacles to Medicare certification which allows a hospice program to be reimbursed at the Medicare designated rates. Primarily, the regulations establish four different levels of hospice care based on the type and intensity of services offered. These include routine home care, continuous home care, inpatient respite care and general inpatient care.⁸¹ Each category represented a separate pre-calculated payment rate, thus establishing a prospective payment system for hospices.⁸² Concurrently, the final regulations imposed an aggregate cap on the Medicare payments. This cap, originally estimated at \$4,232, was subsequently amended to \$6,500.⁸³

One of the most controversial impediments to hospice development contained in the regulations related to the provision of "core" services - services that must be directly provided by each hospice on a routine basis.⁸⁴ Many in the hospice field expressed reservation about requiring certain services to be

78. Tax Equity and Fiscal Responsibility Act of 1982, Pub. L. No. 97-248, 96 Stat. 324 (codified as amended 42 U.S.C. § 1395ww) (1983).

79. SUBCOMM. ON HEALTH, *supra* note 71, at 18.

80. 42 C.F.R. § 418.1 *et. seq.* (1986).

81. *Id.* at § 418.301.

82. Routine home care payment is based on a per diem approach; continuous home care is paid on an hourly rate with a minimum of 8 hours required; the inpatient respite care rate is based on skilled nursing facility costs; and the general inpatient rate is based on the cost experience of hospital-based hospices, which accurately reflects the unique cost experience of hospice inpatients. The specific rates included in the final rules were:

Routine home care	\$ 46.25*
Continuous home care:	
Total continuous care rate	358.67
Rate for 8 hrs.	119.56
Hourly rate	14.94
Inpatient respite care	55.33
General inpatient	271.00

* Subsequently increased to \$53.17 as originally proposed.

Id. at § 418.302.

Additionally, concern about inadequate payment rates resulted in a subsequent across the board \$10 increase in each of the daily rates. Consolidated Omnibus Budget Reconciliation Act of 1985, Pub. L. No. 99-272, 100 Stat. 168 (as codified 42 U.S.C. § 1395f) (Supp. 1987) (effective April, 1986) [hereinafter CORBRA].

83. 42 C.F.R. § 418.309 (1986).

84. Core services include: nursing care, medical social services, physicians services, and counselling. R. Price, *Hospice Care Under Medicare - Updated 10/03/86* (Cong. Res. Service 1986).

provided directly by individual hospices. The general sentiment was that this requirement would make it difficult for many organizations to qualify as hospices and would duplicate existing nursing staff requirements even though these services were available through existing home health agencies.⁸⁵ "Non-core" services,⁸⁶ on the other hand, may be provided either directly by the hospice or under contractual arrangements with other providers; however, the hospice is required to maintain professional management responsibility for all services furnished to patients and their families.⁸⁷ In reality, the "core" services requirement, coupled with apparently inadequate payment rates, has been partially blamed for the low number of Medicare certified hospices to date.⁸⁸

In the more secluded rural hospice setting, there were additional concerns focused on the "core service" provision. In an effort to address this particular concern, the Deficit Reduction Act of 1984⁸⁹ included a waiver provision for rural hospice programs. The final regulations implementing this waiver were eventually promulgated in 1987.⁹⁰

A potentially burdensome regulation necessary for Medicare certification dictates that a hospice may not discontinue or diminish care provided to an individual because of an individual's inability to pay. Thus, when an individual has exhausted his Medicare hospice coverage, the hospice must continue to provide services of the same intensity.⁹¹ This often presents a perceived financial barrier for many of the smaller home health hospice organizations.

Several of the other regulations also present significant restrictions on hospices. First, the hospice election periods are limited to two ninety-day periods and one thirty-day period that must be used in that order.⁹² Second, the regulations require that the total number of inpatient days may not exceed

85. 48 Fed. Reg. 56,013 (1983).

86. Non-core services include: Physical therapy, occupational therapy, speech language pathology services, home health aide, homemaker services, medical supplies, and short term inpatient care. Price, *supra* note 84, at 6.

87. *Id.*

88. As of July 1, 1986, only 279 out of the approximately 1,500 hospices have been certified to participate in the Medicare program. Price, *supra* note 84, at 5.

89. Deficit Reduction Act of 1984, Pub. L. No. 98-369, 98 Stat. 494 (as codified at 42 U.S.C. § 1395x (1984)).

90. The rural waiver provision applies to "hospices that are located in non-urbanized areas as identified by the Bureau of the Census and were operational on or before January 1, 1983." To be eligible for the waiver, the hospice must demonstrate that it has made a good faith effort to hire nurses. These final regulations became effective April 10, 1987 and the waiver period is set for a three year duration. 52 Fed. Reg. 7412, 7413 (1987).

91. 42 C.F.R. § 418.60 (1986).

92. *Id.* § 418.24.

20 percent of the aggregate of all care days.⁹³ Third, a requirement for an interdisciplinary team approach mandates that at a minimum, a physician, a nurse, a social worker and a counselor must be included in the team.⁹⁴ Fourth, the Medicare beneficiary must be deemed to have waived most other Medicare benefits as a consequence of electing hospice care.⁹⁵ As noted, the Consolidated Omnibus Budget Reconciliation Act of 1985⁹⁶ has attempted to address the payment rate shortfall. Public Law 99-272 eliminated the sunset provisions in the original legislation which called for the reevaluation of the hospice program concept before October 1, 1986. This legislation has also permitted coverage of hospice care as an optional Medicaid benefit.⁹⁷

As a result of this latest legislative initiative, the hospice benefit is now a permanent part of the Medicare reimbursement system. Despite this favorable inclusion in the reimbursement system, growth in Medicare certified hospice programs is projected to remain low.⁹⁸ The certification requirements fail to offer any economic incentive for hospice programs to undertake the burdensome process and paperwork necessary to receive payment rates which fall short of covering actual costs of services.⁹⁹ Moreover, several controversial requirements contained in the legislation will need to be modified before Medicare certification status is generally considered a worthwhile benefit for hospice programs.¹⁰⁰

However, many in the hospice industry praise the fact that Medicare has finally recognized hospice as a benefit. While attempts are made to correct the burdensome certification process, hospices should be encouraged to par-

93. The so called "80/20" rule. Tames, *Hospices Chart New Course*, LONG TERM CARE MANAGEMENT, Aug. 1986, at 3.

94. 42 C.F.R. § 418.68 (1986).

95. *Id.* at § 418.24.

96. See COBRA, *supra* note 82.

97. *Id.* Additionally, in recognition of the growing importance of the hospice concept, President Reagan proclaimed November, 1986 National Hospice Month and in his proclamation noted that "[h]ospices are rapidly becoming full partners in the Nation's health care system. Medicare provides a hospice benefit, as do many private insurance carriers. But there remains a great need to increase public awareness about the benefits of hospice care." Proclamation No. 5567, 51 Fed. Reg. 40,959 (1986).

98. Tames, *supra* note 93, at 2.

99. For example, the Northern Virginia Hospice, one of the original hospices in the National Demonstration project, has reported an estimated loss of \$1400 per Medicare patient. Similar results on a national level have placed added stress on hospices to greatly increase philanthropic efforts to subsidize Medicare shortfalls. *Id.* at 3.

100. Modifications in the Medicare requirements for certification must address the following problem areas: "(1) the requirement that hospices provide directly certain core services, (2) provisions that require members of the hospice team to be substantially full-time employees, (3) the payment structure and (4) limits in inpatient care." citation Modifications and added flexibility regarding the issues may represent an effective method for encouraging hospices to participate in the Medicare certification process. *Id.* at 2, 3.

ticipate in the Medicare program as a means of joining in the effort to provide cost-effective care to the terminally ill.

Cost-Effectiveness in a World of Cost Containment

The controversy about hospice reimbursement highlights one of the major concerns about the concept: whether it is a truly cost-effective alternative to conventional care. Initially, no hard statistical studies or data were available to support claims of cost-effectiveness. Subsequently, the National Cancer Institute demonstration project found that an average day of hospice care was about one-fourth as expensive as the average hospital day.¹⁰¹ Moreover, the extensive use of volunteers as well as emphasis on hospice care as an alternative to inpatient hospital treatment were factors mainly credited with holding hospice costs down.¹⁰²

Data from the long awaited National Hospice Study ("NHS"), which was conducted from 1981 to 1983, revealed that patients treated in home care and hospital-based hospice experience lower costs in the last month of life than do patients treated in conventional care.¹⁰³ However, the cost savings revealed by the NHS did not include physician services involved in the hospice demonstration project.¹⁰⁴ The NHS revealed that home care hospital patients averaged \$10,798 in total Medicare inpatient, home care, and nursing home costs. Hospital-based hospice patients averaged \$12,698 and conventional care patients averaged \$14,799.¹⁰⁵ Notably, from the third month prior to death back to the sixth month, costs for hospice patients were actually higher than conventional care.¹⁰⁶ Often the difference in cost was quite significant. However, in the last two months of life, the substitution of less costly home services for inpatient care are primarily responsible for recognized cost savings.¹⁰⁷ Additionally, the hospice focus on palliative care

101. Reiss, *supra* note 40, at 24-25.

102. *Id.* at 27.

103. Brown University was awarded a grant to conduct an independent analysis of HCFA's hospice demonstration project. Titled the "National Hospice Evaluation Study", the study was conducted from 1981 through 1983. The final report was repeatedly delayed due to questions raised by those in the industry regarding the "fairness" of the original conclusions which were based on limited data from the 26 hospice units included in the demonstration project. Subsequent data, on which the 1984 and 1985 reports are based include information on a total of 40 programs. Towne Interview, *supra* note 38. See, Mor & Kidder, *supra* note 43.

104. Since physician costs constitute only about 10-15% of all health care costs during the last six months of life, their exclusion is not likely to have a major effect on the findings. Mor & Kidder, *supra* note 43, at 409.

105. *Id.* at 413.

106. *Id.* at 414.

107. *Id.* at 415.

saves on costs associated with use of expensive ancillary services.¹⁰⁸ Interestingly, the NHS study revealed that the relative intensity of inpatient days experienced by hospice patients decreases substantially as death approaches. On the other hand, conventional care patients actually experience an increase in inpatient care as death approaches.¹⁰⁹

The NHS study concluded that the earlier a patient enrolls in a hospice program, the more expensive the total outlay of services,¹¹⁰ which may tend to offset any cost savings compared with conventional care. However, the cost savings in the last two months of life may more than compensate for this discrepancy.¹¹¹ Overall, longer lengths of stay tend to be more cost-effective. The NHS study also concluded that there were no negative consequences regarding quality of care or the survival of hospice patients.¹¹² Additionally, patient satisfaction was found to be greater in the hospice setting.¹¹³ Specifically, based on the fact that hospice care was not more costly overall, nor harmful in any respect to the patient, the study concluded that the "hospice concept is a cost-effective alternative to conventional care for terminally ill cancer patients."¹¹⁴

SYNOPSIS OF LEGAL AND ETHICAL ISSUES IN CARING FOR THE DYING

In light of the fact that hospice itself represents a departure from the style of medicine practiced in the United States, it is no wonder that this concept, while gaining recognition, has continued to spawn controversy and raise concerns about a host of ethical issues. Therefore, some of the central ethical issues involved must be addressed.

Foremost among the ethical and legal issues related to hospice care is the individual's right to refuse treatment and the right to die.¹¹⁵ Refusing medi-

108. *Id.* at 416.

109. *Id.*

110. *Id.* at 418.

111. *Id.*

112. *Id.* at 420.

113. *Id.*

114. *Id.* Fearing that the emphasis on cost efficiency/effectiveness raises serious questions about the well being of patients and society's valuation of life, Donald Gibson, Ph.D. raises some interesting moral and ethical considerations regarding the focus on cost effectiveness. See Gibson, *Hospice: Morality and Economics*, 24 *GERONTOLOGIST* 4 (1984). See also, Fraser, *Medicare Reimbursement for Hospice Care: Ethical and Policy Implications of Cost-Containment Strategies*, 10 *J. HEALTH POL. POL'Y AND L.* 565 (1985).

115. See generally, PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, *DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT* (1983) [hereinafter PRESIDENT'S COMMISSION]; Jonas, *The Right to Die*, 8 *HASTINGS CENTER REP.* 31 (1978); Reimer, *Legal Analysis of the Right to Die*, Congressional Research Service Report, No. 85-222A (1985).

cal treatment and electing death over continued suffering were once completely alien to the American society. The right to live, no matter what the cost or degree of suffering, was considered the most fundamental of all rights.¹¹⁶ Questions of quality of life and human dignity were not freely discussed. However, public and professional opinions have begun to change. Recognizing the right to self-determination regarding one's health, the President's Commission for the Study of Ethical Problems in Medicine "concluded that the authority of competent, informed patients to decide about their health care encompasses the decision to forego treatment and to allow death to occur."¹¹⁷

It is generally accepted that competent adult individuals are free to accept or reject medical advice and/or treatment for any illness. They are also free to withdraw from such treatment once it is initiated.¹¹⁸ The incompetent patient, or the patient with diminished decision-making capacity, presents a far more difficult situation. In such circumstances, those who are most knowledgeable of the patient's wishes are often called upon to make necessary treatment decisions.¹¹⁹ According to the Ethics Committee of the National Hospice Organization, ". . . [t]heir task is to determine what the patient would have chosen, or, if that is impossible, what is in the patient's best interest."¹²⁰

Decisions related to treatment, or the cessation thereof, often include questions related to withholding or withdrawing nutritional support.¹²¹ In

116. Jonas, *supra* note 115, at 31.

117. See PRESIDENT'S COMMISSION, *supra* note 115, (letter of transmittal from Morris B. Abram, Chairman to The Honorable George Bush, President, United States Senate, March 21, 1983).

118. Jonas notes that the one recognized limitation to withdrawal from treatment that has already begun is in the midst of a "critical phase." "A critical phase would be that between two linked operations or during post-operative care, or similar situations where only the complete therapeutic sequence is medically sane. It must then be considered contracted for as an indivisible whole. Physician and hospital would not have performed the first steps without the patient's commitment to the remainder." Jonas, *supra* note 115, at 32.

119. See generally NATIONAL HOSPICE ORGANIZATION ETHICS COMMITTEE, *Hospice Monograph - Decisions in Hospice* (1985) [hereinafter *Decisions in Hospice*]; Reimer, *supra* note 115; Mishkin, *Decisions Concerning the Terminally Ill: How to Protect Patients, Staff and the Hospital*, 2 HEALTH SPAN, Mar. 1985, at 17; Mishkin, *Making Decisions for the Terminally Ill*, BUSINESS HEALTH, June 1985 at 13.

120. In applying the standard of what serves the best interests of the patient, "the decision makers should determine whether the anticipated benefit of the proposed course of treatment will outweigh the burdens of that treatment for the particular patient, and under the specific circumstances, of each case. *Id.* at 13; PRESIDENT'S COMMISSION, *supra* note 115; In re Conroy, 98 N.J. 321, 486 A.2d 1209 (1985).

121. See generally Mishkin, *Withholding and Withdrawing Nutritional Support*, 1 NUTRITION IN CLINICAL PRAC. 50 (1986).

this context, the use of living wills¹²² is often helpful as a guide to the individual patient's wishes.¹²³ Moreover, in an effort to assist and guide physicians in addressing such concerns with patients and/or their representatives, the American Medical Association's ("AMA") Council on Ethical and Judicial Affairs issued an official opinion on withholding or withdrawing life-prolonging medical treatment.¹²⁴ The opinion states that when the physician's duties of sustaining life and relieving suffering conflict, the choice of the patient or his representative should prevail. Moreover, in treating the terminally ill, the physician should determine if the benefits of treatment, including nutrition and hydration, outweigh the burdens that treatment may impose.¹²⁵

These issues become even more troublesome when there is a difference of

122. The following states have adopted statutory provisions recognizing the legal effectiveness of living wills. ALA. CODE §§ 22-8A-1 to -10 (1984); ARIZ. REV. STAT. ANN. §§ 36-3201 to -3210 (1986); ARK. STAT. ANN. §§ 82-3801 to -3804 (Supp. 1985); CAL. HEALTH & SAFETY CODE §§ 7185-7195 (West Supp. 1985); COLO. REV. STAT. §§ 15-18-101 to -113 (Supp. 1986); 1985 CONN. ACTS 85-606 (Reg. Sess.); DEL. CODE ANN. tit. 16, §§ 2501-2508 (1983); D.C. CODE ANN. §§ 6-2421 to -2430 (Supp. 1986); FLA. STAT. ANN. §§ 765.01 -.15 (1986); GA. CODE ANN. §§ 31-32-1 to -12 (1985 & Supp. 1986); IDAHO CODE §§ 39-4502 to -4506 (1985 & Supp. 1986); ILL. ANN. STAT. ch. 110 1/2, para. 701-710 (Smith-Hurd Supp. 1987); IND. CODE ANN. §§ 16-8-11-1 to -21 (Burns Supp. 1986); IOWA CODE ANN. §§ 144A.1 to .11 (West Supp. 1986); KAN. STAT. ANN. §§ 65-28-101 to -109 (1980); LA. REV. STAT. ANN. §§ 40:12299.58.1 to .10 (West Supp. 1986); ME. REV. STAT. ANN. tit. 22, §§ 2921 to 2931 (Supp. 1986); MD. HEALTH-GEN. CODE ANN. §§ 5-601 to -614 (Supp. 1986); MISS. CODE ANN. §§ 41-41-101 to -121 (Supp. 1985); MO. ANN. STAT. §§ 459.010 to .055 (Vernon Supp. 1986); MONT. CODE ANN. §§ 50-9-101 to -111 (1985); NEV. REV. STAT. §§ 449.540 -690 (1986); N.H. REV. STAT. ANN. §§ 137-14:1 to -:16 (Supp. 1985); N.M. STAT. ANN. §§ 24-7-1 to -11 (1986); N.C. GEN. STAT. §§ 90-320 to -323 (1985); OKLA. STAT. ANN. tit. 63, §§ 3101 to 3111 (West Supp. 1987); OR. REV. STAT. §§ 97.050 to .090 (1985); TENN. CODE ANN. §§ 32-11-101 to -110 (Supp. 1986); TEX. REV. CIV. STAT. ANN. art. 4590h (Vernon Supp. 1986); UTAH CODE ANN. §§ 75-2-1101 to -1118 (Supp. 1986); VT. STAT. ANN. tit. 18, §§ 5251-62 (Supp. 1985); VA. CODE ANN. §§ 54-325.8:1 to :13 (Supp. 1986); WASH. REV. CODE ANN. §§ 70.122.010 to .905 (Supp. 1986); W. VA. CODE §§ 16-30-1 to -10 (1985); WIS. STAT. ANN. §§ 154.01 to .15 (West Supp. 1986); WYO. STAT. §§ 33-26-144 to -152 (Supp. 1986). See generally Note, *Need for a Living Will*, 3 J. CONTEMP. HEALTH L. & POL'Y 253 (1987).

123. COHEN, *supra* note 14, at 130. See generally PRESIDENT'S COMMISSION, *supra* note 115, at 139 (1983); Reimer, *supra* note 115, at 20.

124. Issued in March 1986, the opinion states, in part that, "[l]ife-prolonging medical treatment includes medication and artificially or technologically supplied respiration, nutrition or hydration. . . . At all times, the dignity of the patient should be maintained." AMA Council on Ethical and Judicial Affairs, *Withholding or Withdrawing Life Prolonging Medical Treatment*, 53 CITATION 51 (1986) (Emphasis added) [hereinafter AMA Opinion]. See generally Miles, *The Terminally Ill Elderly: Dealing with the Ethics of Feeding*, 40 GERIATRICS 112 (May 1985); Childress, *Must Patients Always Be Given Food and Water?*, 13 HASTINGS CENTER REP. 17 (1983).

125. AMA Opinion, *supra* note 124.

opinion among the patient, the primary physician, and/or the family.¹²⁶ This situation often requires patience and diplomatic handling by hospice personnel in order to reach the ultimate decision which is in the patient's best interest and reflects the patient's own wishes.

As previously noted, pain control is one of the fundamental tasks of the modern hospice concept.¹²⁷ Because pain is often controlled by prescribing drugs, the potential for drug addiction in the terminally ill patient is an important concern; however, drug addiction is a matter for concern when one anticipates eventually stopping drug therapy.¹²⁸ This is not the case with the hospice patient who remains under the drug therapy until death. Moreover, the utilization of effective polypharmacy should result in relief of pain, not in addiction.

An added ethical/legal issue encountered in the delivery of hospice care is the need to distinguish between the concept of hospice and the issue of euthanasia.¹²⁹ Active euthanasia may be defined as "deliberately inducing death in order to terminate the hopeless suffering or a meaningless existence."¹³⁰ Richard Lamerton, the medical director of St. Joseph's Hospice in London, has capsulized the marked distinction between hospice and euthanasia in the following quote:

To fail to provide for the dying is to fail in a basic duty. The self-evident requirements of a dying man are to have his symptoms relieved and to be allowed to die with dignity and peace of mind. If we evade all the difficult problems he presents, and just kill him, we have failed. Whether such euthanasia were voluntary or not is irrelevant. It is our duty so to care for these patients that they never ask for euthanasia. A patient who is longing to die is not being treated properly. If we are not treating him properly, the solution is to improve our treatment, not to kill him.¹³¹

CASE STUDY: HOSPICE CARE OF THE DISTRICT OF COLUMBIA

The feasibility of establishing a hospice in Washington, D.C. first

126. See sources cited *supra* note 119.

127. See Anspaugh, *supra* note 60 and accompanying text.

128. See Towne Interview, *supra* note 38.

129. See generally DEATH, DYING AND EUTHANASIA (D. Horan and D. Mall eds. 1977); COHEN, *supra* note 14, at 52; Saunders, *The Problem of Euthanasia*, 75 NURSING TIMES 4 (1979); Somerville, *The Dying And Elderly Patient: Issues in Palliative Treatment and Care*, 3 HEALTH L. IN CAN. 74 (1982).

130. See COHEN, *supra* note 14, at 52 (citing RUSSELL, FREEDOM TO DIE (1975)). See also, Meier and Cassel, *Euthanasia in Old Age: A Case Study and Ethical Analysis* 31 J. AMER. GERIATRIC SOC'Y. 294 (1983).

131. Cohen, *supra* note 14, at 56-57.

originated in 1976 in a resolution passed by the Washington Diocesan Council of the Episcopal Church.¹³² Subsequently, in accordance with the task force's recommendations, a hospice was organized with a small paid staff and a core of forty volunteers. Acceptance of the program, itself, by the established medical community was slow and tedious.¹³³ Nonetheless, this group persevered and, in 1979, received their first patient.¹³⁴

Hospice Care of the District of Columbia (hereinafter Hospice Care of D.C.) was initially operated solely as a Medicare certified home care program offering hospice services.¹³⁵ The program operates under a Certificate of Need issued in 1979 to provide hospice home care services.¹³⁶ On December 19, 1986, this program successfully completed the process of becoming a separately certified Medicare hospice program.¹³⁷ Additionally, on December 5, 1986, Hospice Care of D.C. was officially accredited for the delivery of hospice services by the Joint Commission on the Accreditation of Healthcare Organizations.¹³⁸ The major obstacle for such a small program seeking Medicare certification is the requirement that a home care hospice program assume responsibility for inpatient care.¹³⁹ The financial ramifications of such a commitment often preclude small programs from becoming certified and, as a result, force small community-based programs to shift toward becoming more institutionalized.¹⁴⁰ In an effort to solve this dilemma, Hospice Care of D.C., as part of its certification process, has established the necessary contractual relations with area hospitals and the inpatient hospice program of the Northern Virginia Hospice to provide the inpatient care

132. HOSPICE CARE OF THE DISTRICT OF COLUMBIA, 1985 ANNUAL REPORT 3 (1985) [hereinafter ANNUAL REPORT].

133. Many hospices originated as a result of dissatisfaction with the manner in which traditional medicine cared for the dying patient. As a result, the established medical community viewed hospice as a "counter-culture" movement and as antagonistic to the traditional health care industry. Towne Interview, *supra* note 38.

134. ANNUAL REPORT, *supra* note 132, at 3.

135. Towne Interview, *supra* note 38.

136. The District government is currently reviewing recommendations regarding forthcoming licensing legislation. It is anticipated that such regulations covering home care and hospice will be issued sometime in 1987. Additionally, the 1986-1991 State Health Plan will contain a separate section dealing with hospice services. TOWNE, *supra* note 7, at 9.

137. Telephone Interview with Ms. Anne Towne, Executive Director, Hospice Care of the District of Columbia, Washington, D.C. (March 12, 1987) [hereinafter Second Towne Interview].

138. See JCAH Manual, *supra* note 69. The Joint Commission also became involved, in part, to address the problem of "hospice look alike" — programs which hold themselves out as hospices but do not offer the essential core services through a multidisciplinary approach. Second Towne Interview, *supra* note 137.

139. 48 Fed. Reg. 56,009 (1983).

140. Towne Interview, *supra* note 38.

component.¹⁴¹

Hospice Care of D.C., located in downtown Washington, D.C., continues to experience gradually increasing acceptance from the medical community. In 1985, this program provided services to one hundred and six D.C. residents,¹⁴² the majority being from the northwest quadrant of the city.¹⁴³ This is an appreciable increase over the sixty-eight patients served in 1984.¹⁴⁴ Patient mix, in 1985, was approximately equal in terms of racial representation; however, slightly more females were admitted in 1985 than males.¹⁴⁵ Patients ranged in age from eighteen to ninety-nine years with the average age being seventy-two.¹⁴⁶ It should be noted that Hospice Care of D.C. has not developed pediatric expertise due to a lack of community requests for services.¹⁴⁷

In the developmental phases of the hospice concept, patient admission eligibility was often predicated on a projected life expectancy of six months.¹⁴⁸ Today, Hospice Care of D.C. does not use this approach. Rather, it prefers to base admission more on the fact that the patient is entering the end-stage of an illness as opposed to a chronic state.¹⁴⁹ In 1985, patients averaged forty-five days in the program with a range from one to two hundred and fifty-six days.¹⁵⁰ The average daily census for the program was twelve patients.¹⁵¹

In order to be eligible for services from Hospice Care of D.C., the patient must require physical support, emotional comfort and should not be seeking a cure for his disease, Hospice Care of D.C. also requires the patient to live in the District of Columbia and have someone who is willing and able to assume responsibility for coordinating the patient's care.¹⁵² This last re-

141. Inpatient hospice services are currently offered at the Washington Home and the Hospice of Northern Virginia. Holy Cross Hospital in Silver Spring, Md. has recently received approval for an eight bed free-standing hospice center which should be operational by 1989. *Id.*

142. ANNUAL REPORT, *supra* note 132, at 5.

143. In 1985, the following figures represented patient origin by city quadrant: NW-55; NE-25; SE-19; SW-7. HOSPICE CARE OF THE DISTRICT OF COLUMBIA, DEMOGRAPHICS FOR PATIENTS (1985)[hereinafter DEMOGRAPHICS].

144. ANNUAL REPORT, *supra* note 132 at 5.

145. Patients by race and sex for fiscal year 1985: Black - 56, White - 50; Female - 54; Male - 52. DEMOGRAPHICS *supra* note 143.

146. ANNUAL REPORT *supra* note 132, at 5.

147. Pediatric programs are available through the Hospice of Northern Virginia and Childrens Hospital National Medical Center home care program. Towne Interview, *supra* note 38.

148. *Id.*

149. *Id.*

150. ANNUAL REPORT, *supra* note 132, at 5.

151. *Id.*

152. ANNUAL REPORT, *supra* note 132, at 4.

quirement tends to limit the population eligible for admission,¹⁵³ particularly given the demographics of the District, where there are an increasing number of elderly, single women and black men¹⁵⁴ who live alone.

The primary goal of the hospice care team is to deal with the pain and suffering of terminal illness from all perspectives: physical, emotional, spiritual, and financial.¹⁵⁵ To that end, the Hospice team consists of a physician, a nurse, a social worker, a chaplain, and a cadre of trained volunteers. Services are available on a 24-hour basis.¹⁵⁶ Through this core group, the essential services are offered, including bereavement services for the family until thirteen months after the patient's death. The hospice physician either assumes total responsibility for the patient's care or works in consultation with the individual's private physician.¹⁵⁷

In concert with the basic hospice philosophy, pain is treated by careful attention to the administration of the appropriate dose of medication appropriately timed.¹⁵⁸ All symptom control is aimed at palliative, as opposed to curative, treatment - making the patients as comfortable as possible while at the same time allowing them to remain as functional as possible.

Volunteers form the core of this hospice program. All potential volunteers are carefully screened and, if accepted, go through twenty-five hours of training. In its eight years of existence, Hospice Care of D.C. has had over two hundred volunteers, many of whom have experienced the terminal illness and death of a close family member.¹⁵⁹

In terms of reimbursement for services, patients serviced by Hospice Care of D.C. are predominantly covered by Medicare home care benefits.¹⁶⁰ Blue Cross and Medicaid comprise the next two largest groups, while only two percent of patients seen have no insurance.¹⁶¹ Due to the inadequacy of the insurance reimbursement, Hospice Care of D.C. offsets only twenty-five percent of its budgeted expenses through this payment source.¹⁶² The remaining 75 percent of income comes from community sources (i.e., fund raising,

153. Towne Interview, *supra* note 38.

154. On occasion Hospice of D.C. has accepted patients with no primary care giver available in the home. This arrangement presents one of the greatest challenges to a hospice program: to be able to establish a network of volunteers to service the patient who lives alone. *Id.*

155. ANNUAL REPORT, *supra* note 132, at 3.

156. TOWNE, *supra* note 7, at 13.

157. *Id.*

158. Towne Interview, *supra* note 38.

159. *Id.*

160. In 1985, 66 percent of insurance reimbursement was from Medicare. TOWNE, *supra* note 7, at 16.

161. Blue Cross accounted for 17 percent; Medicaid 10 percent. *Id.*

162. The following information from 1985 related to reimbursement highlights the inadequacy of these payment sources.

foundations, grants).¹⁶³ Available data on total cost per patient reveals that, in 1982, the average total cost per patient was \$4,692 (based on 65 patients), as compared to \$3,240 per patient for the one hundred and six patients serviced in 1985.¹⁶⁴

It is anticipated that the fiscal picture should improve now that Hospice Care of D.C. is certified to receive reimbursement under the Medicare hospice benefit program. The difference between the daily rate reimbursed under the Medicare hospice benefit and the per visit rate under the Medicare home care benefit being primarily responsible for the improvement. Also, a general improvement has been noted in terms of hospice coverage offered by other third party reimbursers.¹⁶⁵ Because hospice benefits have become a more accepted part of third party payor coverage, the emphasis of hospice providers is shifting from encouraging third party payers to include such a

	<u>Hosp. D.C. Charge</u>	<u>Hosp. D.C. Cost</u>	<u>M'care reimb.</u>
Nurse visit	\$ 75.00	\$305.00	\$62.00
Social Worker Visit	\$100.00	\$312.00	\$93.00

Id.

163. *Id.* at 17.

164.

Total Cost Per Patient Comparison

<u>1982</u>		<u>1983</u>		<u>1984</u>		<u>1985</u>	
<u>Cost</u>	<u>Pt.</u>	<u>Cost</u>	<u>Pt.</u>	<u>Cost</u>	<u>Pt.</u>	<u>Cost</u>	<u>Pt.</u>
\$4692	65	\$9548	37	\$4707	68	\$3240	106

Part of the reduction in 1985 is due to the use of student RNs and volunteer RNs who performed 21 percent of all home visits. *Id.* at 15. In order to properly evaluate the average cost per patient, it is necessary to consider the intensity of services received. The following figures assist in the evaluation of figures for 1984 and 1985. On the average each patient received the following:

	<u>1984</u>	<u>1985</u>
RN visits	6	5
Social worker visits	2	3-4
Physician visits	2	2
Volunteer visits	3	10
Chaplain	1	23
Average length of stay	32 days	45 days
Total patients	68	106
Average costs/pt.	\$4704	\$3240
Cost per day	\$ 147/day	\$ 72/day

It is important to emphasize that services must be available on a 24 hr./7 day a week basis. Additionally certain administrative costs are included and are spread out over the total number of patients served. Telephone Interview with Ms. Anne Towne, Executive Director, Hospice Care of the District of Columbia, Washington, D.C. (March 16, 1987) [hereinafter Third Towne Interview].

165. The insurance benefits offered by 85 of the top 100 employers in D.C. now offer some form of hospice benefit. Additionally, 95 percent of the plans offered to federal workers contain some sort of hospice benefit. TOWNE, *supra* note 7, at 17.

benefit to improving the scope of the hospice benefit offered.¹⁶⁶

The major ethical and legal problems encountered by Hospice Care of D.C. are typical of hospices in general. The issue of nutrition hydration is always present and is handled based on patient choice.¹⁶⁷ As a general rule, intravenous therapy is not used.¹⁶⁸ Additionally, problems arise when the patient and family members differ as to the course of treatment.¹⁶⁹ Other dilemmas, as noted by Ms. Towne, Executive Director of Hospice Care of D.C, are encountered when patients live alone,¹⁷⁰ or are indigent with no source of payment.¹⁷¹ There are no set solutions for dealing with these issues. Rather, they are handled on an individual basis.

Hospice Care of D.C. places great emphasis on the need to continually reevaluate the appropriateness of treatment and services offered by the hospice program to the individual patient.¹⁷² Some patients might be better served by transfer to a regular home care program, or, as the need arises, to an inpatient facility. Additionally, on occasion, some patients may stabilize and temporarily check out of the program to seek aggressive treatment while others may actually experience remission.¹⁷³ Hospice Care of D.C. has actually had sixteen patients leave their program due to remission.

Although the vast majority of patients serviced have a primary diagnosis of terminal cancer, Hospice of D.C. has cared for patients in the end stages of other diseases such as AIDS, heart disease and amyotrophic lateral sclerosis (Lou Gehrig's disease). As the program continues to grow and assess its progress, one element of review will include evaluating potential areas of expansion.

CONCLUSION

The traditional American health care system and its provider members have prided themselves on the technologically-oriented advances in various treatment modalities. A visit to any intensive care unit will attest to this fact - one's visual senses are overwhelmed with a myriad display of monitors, flashing lights, tubes and elaborate equipment while one's audio sensitivities are assaulted by a barrage of beeps, hisses and alarms. It often appears that

166. Towne Interview, *supra* note 38.

167. *Id.*

168. *Id.*

169. *Id.* See generally *supra* note 119.

170. See *supra* note 154.

171. Towne Interview, *supra* note 38.

172. *Id.*

173. From 1979 to 1985 Hospice Care of D.C. experienced the following: at-home deaths - 246; in-patient facility deaths - 129; living discharges - 24 (i.e., remissions - 16; withdrawal - 1; families unable to continue in program - 7). Third Towne Interview, *supra* note 164.

health care providers have lost sight of the purpose behind all the technology - to, in reality, restore the individual to a functional level of dignified existence.

More frequently, however, the system is now acknowledging that it cannot "win" every battle. Therefore, the greater achievement is to switch the focus of care to assist the patient and his family to prepare for death in a meaningful and quality-oriented manner. A terminal diagnosis is an initially devastating occurrence for patient and family alike. To enable these individuals to spend their last weeks or months pain-free and in the comfort of familiar home surroundings represents a more humane and respectful method of treatment which the system can provide. This approach is receiving increasing acceptance and is more readily available to greater numbers of the terminally ill due to the revitalization and growth of the hospice philosophy.

In order to ensure continuing access to the meaningful services provided by the various hospice models, financial arrangements to cover these services must be forthcoming. However, the complicated nature of Medicare hospice regulations has left many smaller, independent hospice programs struggling to qualify for reimbursement. This fact, combined with the increasing competitive nature of the health care field, has resulted in the merging of many independent hospices with larger, more financially stable, health care systems.¹⁷⁴ Although Medicare reimbursement is a cumbersome process, it may be the sole source of financial survival for many hospice programs. In order to profit under this reimbursement system, it is necessary for hospices to increase admissions, as well as the length of stay for patients.¹⁷⁵

In an effort to encourage Medicare certification, HCFA and representatives of the hospice industry must try to compromise on many of the issues which currently curtail application for certification. In particular, a reasonable solution must be reached regarding the provision of "core services" if the hospice concept is to continue to grow without duplicating existing services. The rural hospice waiver is a gesture in the right direction.

Hospice programs traditionally have focused on terminally ill cancer patients. Given the increase in the incidence of AIDS as well as the heightened focus on Alzheimer's disease, the hospice method of care holds great promise for patients suffering from these illnesses. The hospice industry, without sacrificing its basic philosophy, should demonstrate an increased ability to adapt to caring for a variety of terminally ill or end-stage patients if the

174. *The Future of Hospice Care* MED. & HEALTH [Perspectives] Sept. 22, 1986.

175. *Id.*

concept is to continue to expand and meld with the traditional health care delivery system.

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