

THE ROLE OF THE PHYSICIAN IN END-OF-LIFE CARE: WHAT MORE CAN WE DO?

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Less than 100 years ago, virtually everyone — from the youngest to the oldest — had an intimate experience of the two major events of life: birth and death. These were known and accepted landmarks of a life and were respected as such. In the case of death, even physicians — perhaps especially physicians — knew the limitations of their calling. Their role was seldom to cure since there was little they could do, but it was always to care and comfort the dying person and the family. This was an accepted responsibility and goal of the profession.

Despite the incredible scientific progress of the ensuing years, even at the mid-century, it was said that for the first time a patient began to have a better than even chance of benefitting from an encounter with a physician. Continuing progress, however, has improved this percentage enormously in favor of the patient, and physicians began to believe in the power of science and technology to realize the age-old dream of extended life. Death became the “enemy” — to be defeated at all cost — and subsequent generations of medical students have been indoctrinated with this philosophy. The long-term impotence and ambivalence of physicians toward death became replaced by the promise of a new power and prestige. In time, the magic of science and technology was offered to the patient in place of the traditional fiduciary relationship of the physician. Physicians began to *do to* their patients, rather than *be with* their patients. Soon the dying patient became an embarrassment and rebuke to the newly held power and prestige, and physicians began “to pass by on the other side” — to avoid the dying patient and his/her family. An equal affront were the often excessive attempts at intervention done in the name of preserving life.

Of course, it was not alone the successful seduction of the medical profession by the promises of science and technology that led to the emergence of a “conspiracy of silence” where death was concerned. The entire culture — at least in the West — was drawn into

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the vortex of a self-interested, self-serving mode that denied the normal progression of aging and life. Our society embarked upon an era that extolled youth, the "here and now," materialistic satisfaction and expectations of immediate results — and, of course, the denial of death.

The past several decades have seen a significant countermovement — led by persons such as Elizabeth Kubler-Ross and Dame Cicely Saunders — one that has led us back to a reconsideration of the place of death and dying in our society and in the life span. Belatedly, even the medical profession is re-examining its role in end-of-life care and there are now specialists in such care who are developing more effective and humane methods of relief for the dying. In part, this is due to the efforts of several of the major foundations which have funded large-scale studies of public attitudes and patient concerns about the dying experience. The net effect has been to highlight the serious deficiencies in our care for the dying.

At nearly the last minute, the medical profession is becoming aware of and accepting responsibility to overcome these deficiencies and to make renewed efforts to better meet the needs of end-of-life care. Organizations such as the World Health Organization (WHO), the American Board of Internal Medicine (ABIM), the American Academy of Hospice and Palliative Medicine (AAHPM), and the American Medical Association (AMA) have all proposed recent bold initiatives in end-of-life care. Indeed, it is the efforts of the last — the AMA — that will be featured in this article.

I. SOME FACTS AND FEATURES OF DYING IN AMERICA

The benefits of the science and technology referred to above have resulted in remarkable enhancements in health and life expectancy. In 1900, the average life-expectancy was some 50 years, by 1995, it was estimated to be 75.8 years.¹ In addition, there has been a complete change in the causes of death — from acute, infectious diseases to chronic, long-term illnesses.² While people still die suddenly of unexpected causes, such as heart attacks and accidents, the more common trajectories of death consist of patterns of steady decline from a progressive disease such as cancer, with a predictable "terminal phase," or of a slow decline with periodic crises and "sudden" death in

1. See Committee on Care at the End of Life, Institute of Medicine, *APPROACHING DEATH: IMPROVING CARE AT THE END OF LIFE* 35 (Marilyn J. Field & Christine K. Cassel eds., 1997) [hereinafter *IMPROVING CARE AT THE END OF LIFE*].

2. See *id.* at 37.

the case of advanced chronic illness and disabilities, such as congestive heart failure or emphysema.³

The nationwide 1996 Gallup Survey indicated that 9 out of 10 adults would prefer to be cared for at home if terminally ill with six months to live.⁴ Yet, in 1992, 57% of all deaths occurred in hospitals, with an additional 17% in nursing homes.⁵ As some indication of a shift in patterns of care, however, some 17% of deaths in 1995 occurred in hospice care institutions.⁶ Indeed, 84% of adults in the Gallup survey expressed interest in a comprehensive program of care, such as hospice.⁷ Unfortunately, the median stay in hospice is only 36 days, and shrinking, and some 16% of patients die within 7 days of admission.⁸ All of our studies appear to indicate that what people want is to die at home, free of machines, alert yet free of pain and surrounded by family. What they fear most is dying in an institution, alone, hooked up to a machine, in pain, and being a burden to their family.

How realistic is this last fear? From what we know, 90% of adults believe it is the family's responsibility to care for the dying.⁹ Yet, "being a burden to family and friends" was cited by 40% of adults as the greatest fear associated with death.¹⁰ Three out of four adults (75%) report that they have experienced the death of a family member or a close friend in the past five years.¹¹ Unfortunately, 31% of the families in the SUPPORT study reported losing most of their savings or their major source of income (29%) in the process of caring for the patient, and that a family member often had to quit work or make another major life change.¹²

Until recently, most physicians have focused largely on the treatment and management of pain in terminal patients. And it is true that pain is probably the symptom most patients fear — reported by

3. See *id.* at 27-28 (illustrating prototypical death trajectories).

4. See THE GALLUP ORGANIZATION, KNOWLEDGE AND ATTITUDES RELATED TO HOSPICE CARE (1996) (highlighting a poll conducted for the National Hospice Organization; on file with author).

5. See IMPROVING CARE AT THE END OF LIFE, *supra* note 1, at 39.

6. See *id.* at 40.

7. See THE GALLUP ORGANIZATION, *supra* note 4.

8. See Nicholas A. Christakis & Jose J. Escarce, *Survival of Medicare Patients After Enrollment in Hospice Programs*, 335 NEW ENG. J. MED. 172, 172 (1996); IMPROVING CARE AT THE END OF LIFE, *supra* note 1, at 40-41.

9. See THE GALLUP ORGANIZATION, *supra* note 4.

10. See *id.*

11. See *id.*

12. See Kenneth E. Covinsky et al., *The Impact of Serious Illness on Patients' Families*, 272 JAMA 1839, 1841 (1994).

45-55% of patients at the end of life.¹³ However, nausea, anorexia, constipation, and fatigue, as well as the psychological symptoms of depression and anxiety are frequently reported. What is clear is that few of these symptoms are comprehensively treated outside of a hospice or palliative care service. Pain is usually under treated, (42% of patients in one major study),¹⁴ while the rest tend to be overlooked or ignored. Indeed, Portenoy et al. state that inpatients report an average of 18.5 symptoms per patient, while outpatients have an average of 9.3 symptoms per patient.¹⁵

The fact is that patients at the end of life usually exhibit a wide range of suffering and of symptoms that include the physical, psychological, social and spiritual dimensions of the experience, and that care for the dying must include attention to each dimension. Recently, the ABIM listed the following physician competencies as essential in end-of-life care (see Table 1),¹⁶ and the new specialty of palliative medicine pays special attention to these competencies.

13. See Jane Ingham & Russell K. Portenoy, THE MEASUREMENT OF PAIN AND OTHER SYMPTOMS in OXFORD TEXTBOOK OF PALLIATIVE MEDICINE 203, 204 (Derek Doyle et al. eds., 2d ed. 1998).

14. See Charles S. Cleeland et al., *Pain and Its Treatment in Outpatients with Metastatic Cancer*, 330 NEW ENG. J. MED 592, 592, 595 (1994).

15. See R.K. Portenoy et al., *Symptom Prevalence, Characteristics and Distress in a Cancer Population*, 3 QUALITY LIFE RES. 183, 183-89 (1984).

16. See AMERICAN BOARD OF INTERNAL MEDICINE, CARING FOR THE DYING: IDENTIFICATION AND PROMOTION OF PHYSICAL COMPETENCY 41 (1998).

TABLE 1¹⁷
 PHYSICIAN COMPETENCIES IN END-OF-LIFE CARE

COMPONENTS	CORE COMPETENCIES
Medical Knowledge	Palliative care <ul style="list-style-type: none"> • assessment and treatment of psychological distress • pharmacologic and non-pharmacologic treatment of pain and other symptoms
Interviewing/ Counseling Skills	Listening Truth telling Giving bad news Discussing dying as a process Dealing with families of dying patients
Team Approach	Understanding multidisciplinary nature of end-of-life care — physician, nursing staff, social services, palliative care or hospice team, pharmacist, chaplain, patient, patient's family, patient advocate Promoting collegiality Enhancing ability of team members to fulfill professional responsibilities
Symptom and Pain Control Assessment and Management	Communication skills Comfort Use of opioids, sedation, or adjuvant analgesics, NSAIDs Control of dyspnea, anxiety AHCP and WHO guidelines
Professionalism	Altruism Non-abandonment Respect for colleagues Accountability Honoring patients' wishes Confidentiality Transference and countertransference
Humanistic Qualities	Integrity Respect Compassion Courtesy Sensitivity to patients' needs for comfort and dignity
Medical Ethics	Advance directives DNR/DNI orders Nutrition/hydration Conflicts of interest Futility Double effect Surrogate decision making Physician-assisted suicide

17. Reproduced with permission from AMERICAN BOARD OF INTERNAL MEDICINE, *supra* note 16.

Death has often been viewed as a failure, rather than as an opportunity. Far too often, the potential for significant gains at the end of life has been overlooked. Death can be a transformative time — a time to finish personal and family issues, to create final memories, exchange gifts, say good-bye and find spiritual peace.¹⁸

II. THE AMA'S INITIATIVE FOR CARE AT THE END-OF-LIFE

In 1998, stimulated by the establishment of an End-of-life section within its new Institute for Ethics, and the receipt of a large grant from the Robert Wood Johnson Foundation to educate physicians for enhanced end-of-life care, the AMA set an association-wide initiative for care at the end of life as its number one priority.¹⁹ Utilizing its ability to convene, coordinate, and influence, the AMA initiative includes and involves all relevant AMA Councils and units, the various components of the Federation and its own Advocacy Resource Center, to support and implement the following goals: 1) improve the quality of care delivered by physicians; 2) improve planning for end-of-life care, and; 3) improve the experience of dying in the US.

In setting this initiative, the AMA has four targets: 1) health professionals, including both physicians and related health professionals; 2) legislative and regulatory bodies; 3) educational institutions, and; 4) the public, including patients, families, and communities. Specific objectives and strategies have been developed for each targeted area.

The AMA priorities for end-of-life care include: 1) articulating and disseminating a vision; 2) developing a consensus process for standards of care; 3) improving professional education; 4) supporting the development of palliative medicine as a discipline, and finally; 5) developing and implementing legislative and regulatory strategies.

Educating Physicians for End-of-life Care

The centerpiece of the AMA's initiative is the Educating Physicians for End-of-life Care (EPEC) Program, a collaborative effort, with major support from the Robert Wood Johnson Foundation.²⁰ Its goals are to 1) define the essential skills required for quality end-of-life care; and 2) train a cadre of physician trainer/educators, who will,

18. See generally IRA BYOCK, *DYING WELL: THE PROSPECT FOR GROWTH AT THE END OF LIFE* (1997).

19. See American Medical Association, *The EPEC Home Page* (visited Feb. 25, 1999) <<http://www.ama-assn.org/ethic/epec/index.htm>>. For more information on the EPEC Project, contact the American Medical Association's Institute for Ethics at 515 N. State Street, Chicago, IL 60610 or call (312) 464-4979.

20. See *id.*

in turn, teach these skills to practicing physicians throughout the United States.

Design of the Curriculum

After an extensive literature review and assembly of over 200 available curricular and educational resource materials by project staff, two advisory panels were formed, made up of the nation's leading experts in palliative and end-of-life care. From the beginning, it was decided that the curriculum should be self-contained, reproducible, and adaptable to the many formats of continuing medical education (CME). It also should be practical, case-based and consistent with principles of adult learning.

The format of the curriculum consists of sixteen coordinated, but stand-alone learning modules offered over a two-day period. Twelve of these are designed to be approximately fifty minutes in length and presented in a workshop setting. This length permits the subsequent presentation of each modular topic within the structure of an individual grand rounds or classroom format. Larger allocations of time will accommodate multiple combinations of the modules. Four of the modules are more didactic in nature, and cover orienting and factual material presented in a formal or plenary format. The specific "training of trainers" portion of the program is four hours in length, and takes place on the half day following the two-day educational format.

The workshop topics include:

- Module 1 — Advance Care Planning
- Module 2 — Communicating Bad News
- Module 3 — Whole Patient Assessment
- Module 4 — Pain Management
- Module 5 — Physician-Assisted Suicide
- Module 6 — Anxiety, Delirium, Depression
- Module 7 — Goals of Care
- Module 8 — Sudden Illness
- Module 9 — Medical Futility
- Module 10 — Common Physical Symptoms
- Module 11 — Withholding/Withdrawing Treatment
- Module 12 — Last Hours of Living
- Plenary One — Gaps in End-of-life Care
- Plenary Two — Legal Issues in End-of-life Care
- Plenary Three — Elements of End-of-life Care
- Plenary Four — Next Steps

Workshop methods include the use of trigger tapes, slide sets, interactive participant exercises, workbook exercises, and take-home

material. Plenary methods include the use of video tapes, lectures, discussion, and questions, along with pre and post testing of the participants and feedback and evaluation of the program. Materials include the EPEC workbook, a trainer's manual, and a video containing the various introductory and factual materials, as well as trigger tapes for discussion purposes.

Preliminary events in rolling out the EPEC program consisted of a pilot presentation of a plenary session and two modules at the AMA Leadership Conference on March 8, 1998, in Washington, D.C., and a subsequent National Conference for leaders in health and end-of-life care was held in Chicago on May 11, 1998. In addition, four regional conferences were held in January, February, and March of 1999 at four geographically separate sites in Phoenix, Atlanta, Boston, and Chicago. Additional meetings are planned.

Companion products developed by staff include the EPEC Speaker's List, a listing of available speakers or different topics on end-of-life care, including their preferred subjects, formats and audiences.²¹ Second, the staff has assembled an EPEC Resource Guide, listing available teaching materials on the subject.²² Third, at the end of the project, staff will publish the EPEC Compendium, a self-directed learning program that will be made available to physicians across the country in late 1999.²³ Finally, at the conclusion of the project, an EPEC monograph containing a summary of key concepts and materials from the EPEC project will be disseminated to practicing physicians throughout the United States.²⁴

Selection of Participants for the EPEC Training

As a result of the introductory presentation of the program at the two national meetings, the EPEC office received an overwhelming number of requests for training from physicians and health care organizations, many of the latter asking to send teams of physicians for the training. In the end, over 500 completed applications were received for the 260 available places, and subjected to a rigorous screening process. In the end, 270 applicants were selected, including some from related health professions.

As expected, the largest number of applications (191) came from seven of the bigger states, especially those with large populations of

21. *See id.*

22. *See id.*

23. *See id.*

24. *See id.*

seniors and existing hospice and palliative care organizations. (See Table 2).

TABLE 2
LARGEST STATES

	Applied	Accepted
California	34	15
Florida	33	23
Illinois	29	17
New York	29	20
Texas	26	13
Arizona	20	8
Michigan	20	14
TOTAL	191	110 (57%)

Of interest were the states from which there were no applications: Arkansas, Idaho, Montana, South Carolina, and Wyoming. Three of these are in the rural west and their absence may reflect the lack of available services as well as the tradition of self-reliance.

Future Plans

The goal of the EPEC program is to train a cadre of physician-trainers who will in turn train others, utilizing the training materials developed. Follow up and evaluation of this group are built into the program and it is hoped that another round of primary training workshops can be implemented.

III. THE END-OF-LIFE CARE TEAM

This presentation would be seriously deficient if we did not make clear that the assigned topic was to focus on the special need for physicians to do better. No physician works alone, however, especially in end-of-life care. The need for the interdisciplinary team in such care is a recognized fact. The enormous variety of needs that dying patients and their families, as well as their caretakers exhibit, requires a vast panoply of skills and competencies to meet those needs. Such a range of skills and competencies calls for teamwork among a wide variety of health-related and other professionals: including nurses, pharmacists, social workers, speech, physical and occupational therapists, as well as lawyers and clergy.

Thus, this discussion of the role of the physician and of the AMA should not be interpreted as a narrow, provincial view of professional roles in end-of-life care. Rather, without the collaboration of a highly

skilled and devoted team of health professionals, health care at the end of life will remain hopelessly mired in the ignorance and lack of coordination of the past — and present.