



The American College of Surgeons

Statement on Principles Guiding Care at the End of Life

The following “Principles Guiding Care at the End of Life” were developed by the American College of Surgeons Committee on Ethics and were approved by the Board of Regents at its February 1998 meeting.

- Respect the dignity of both patient and caregivers.
- Be sensitive to and respectful of the patient’s and family’s wishes.
- Use the most appropriate measures that are consistent with the choices of the patient or the patient’s legal surrogate.
- Ensure alleviation of pain and management of other physical symptoms.
- Recognize, assess, and address psychological, social, and spiritual problems.
- Ensure appropriate continuity of care by the patient’s primary and/or specialist physician.
- Provide access to therapies that may realistically be expected to improve the patient’s quality of life.
- Provide access to appropriate palliative care and hospice care.
- Respect the patient’s right to refuse treatment.
- Recognize the physician’s responsibility to forego treatments that are futile.

Introduction and Historical Background of Palliative Care: Where Does the Surgeon Fit in?

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This is the first in a planned monthly series addressing end-of-life issues written for and by surgeons.

Divinum est sedare dolorem—Blessed are those who treat pain.

GALEN

Following the seminal work in modern hospice care by Dr Cicely Saunders in Great Britain, the past two decades have seen increasing attention focused on end-of-life issues. At precisely the time western medicine witnessed the increased application of technology to all aspects of disease management, hospice philosophy gently shifted the primary purpose of medical intervention from control of disease to the relief of suffering in patients with terminal illness. During its evolution, principles of the hospice concept came to be applied earlier in the course of ultimately incurable conditions, and were referred to collectively as *palliative care*. In 1987, palliative medicine became recognized in Great Britain as a specialty.

In 1990 the World Health Organization defined palliative care as “The active and total care of patients whose disease is not responsive to curative treatment. Control of pain and other distressing symptoms, and of psychological, social, spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are applicable earlier in the course of the illness in conjunction with anticancer treatment.”

Substituting the more general word, “disease” for “cancer” in this definition, one can see that the concept clearly applies to a wider spectrum of illness that could embrace entities as diverse as congenital anomalies, trauma, and cardiovascular disease. Another definition of palliative care is “care that strives to maintain the integrity of a person and his or her family’s life quality of

life through the course of incurable illness.”² Many incurable diseases that were rapidly fatal in the past have become more chronic incurable illnesses, suggesting both a new and ancient therapeutic strategy of coexistence with illness rather than relentless attempts to extirpate or eradicate it. Recent insights into the biology of cancer or the epidemiology of trauma would lead one to believe that the concept of “cure” may be a hope-sustaining myth that often results in blindness to suffering or lost opportunities for other forms of growth.

The 1990s saw a proliferative phase of palliative care innovation and institutions in countries around the world, including the United States. The widening spectrum of disease and life expectancy encountered in palliative care led to the inevitable arrival of the concept at the doorstep of many specialties, including surgery. With their significant presence in the setting of advanced and incurable illness, surgeons and surgical institutions could not indefinitely avoid the social, psychological, and spiritual challenges encountered there.

Despite the need for surgeons to care for this highly vulnerable population of patients, conceptualization of success and failure by the standards of scientific materialism provided formidable barriers to their effective and welcomed participation. In 1997 we suggested in a brief article³ that surgeons have an opportunity to “regain lost ground” with our patients, ground that has been ceded to the intrusions of managed care, litigation, and unrealistic expectations, all of which are often mirrored in our mutual sense of cynicism, isolation, and hopelessness. How uncharacteristic for surgeons not to rise to the challenge of the most difficult illnesses where our timely, competent, and lasting presence is most desperately needed!

Many have recognized that the beginning of reclaiming ground in the war against our patients’ and our own suffering is to restore the integrity of our relationships with our patients. In his Presidential Address to the 1990 Clinical Congress of the American College of Surgeons,

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Frank C Spencer identified the personal, intimate bond that develops between surgeon and patient as one of the four distinct activities of surgery, describing it as “a strong sense of commitment that overrides all other considerations.”⁴ This is why listening and communication skills have achieved primary status in palliative care. The other pillar on which good palliative care rests is the aggressive relief of pain in all its varied forms: physical, psychological, social, and spiritual. In aggregate, these different pains were referred to as “total pain”⁵ by Cicely Saunders, calling on the experiences of work with dying patients whom she served in the capacity of nurse, social worker, and, ultimately, as a physician. Palliative care identifies total pain—not disease—as “the enemy.”

Where there are great expectations there is frequently great doubt. Surgeons may cognitively appreciate the virtue of palliative care while remaining uncomfortable with its emotional challenges and frequent ambiguities. Surgeons have always been proud of their decisiveness—“Often right, but never in doubt.” The confident, determined optimism of a surgeon may seem at odds with the self-doubt and introspection necessary for empathy, the most critical capacity in palliative caring. With respect to empathy, Sherwin Nuland wrote, “We cannot understand others, particularly the suffering of others, without understanding ourselves. . . . Only by facing our own uncertainties and fears, can we feel enough of the uncertainties and fears of others that we can help them through their most perilous hour.”⁶

The surgical personality has evolved from one that distanced itself from patients’ physical distress out of psychological necessity because of the consequences of crude concepts and interventions, to the contemporary interactive or reciprocating personality made possible by refinements in these concepts and interventions. This evolution may provide a new opportunity to rebalance decisiveness with introspection, detachment with empathy. On reflection, this evolution in our clinical conduct parallels the changes in our understanding of physics, one of the scientific underpinnings of our understanding of reality. The Cartesian/Newtonian view of reality is gradually being complemented by the perspective of quantum theory, in which uncertainty is necessary for identity and where the observer is changed by the observed.⁷

Despite the psychological disquietude surgeons may experience in their encounters with advanced, incurable illness, they may be heartened by recollection of surgery’s

past great accomplishments in its response to the problem of human suffering. The management of burns since World War II stands as a great scientific, social, and moral achievement, and few would argue that a burn patient presents the most compelling image of suffering imaginable. Burn care, which begins with immediate pain relief and is sustained by an interdisciplinary process that accommodates a patient to a chronic disease process of ongoing growth and healing, stands as the most well developed model of palliative care in surgery. It is no accident that many eloquent surgical voices in palliative and hospice care have had experience with burns and trauma. This is where we began our evolutionary journey as surgeons, a journey in which our capacity to respond promptly and effectively to acknowledged suffering preceded all that we have accomplished since.

In addition to burn care, great surgeons such as J Englebert Dunphy have written with profound insight and compassion about the care of some of the most vulnerable of patients: those with advanced cancer.⁸ In another realm, one of the great accomplishments of cardiovascular surgery, coronary artery bypass grafting, commenced as an attempt to relieve the pain of angina even before the procedure’s life-prolonging potential could be demonstrated. In addition to these accomplishments, many surgeons were and have since become active in hospice care—the preeminent model of palliative care—since the arrival of the idea in North America in the 1970s.

A vast treasure of information and experience in the care of those with complex, highly symptomatic, ultimately fatal illnesses has accumulated in the nonsurgical fields of medicine during the past quarter century. This knowledge in the form of articles, books, education, and training awaits introduction to the surgical disciplines where penetration has previously been scant.⁹ We may ask ourselves why all this information about the care of the incurable and the dying has not penetrated sooner, and likely it is in part because of culture differences between surgery and nonsurgical specialties. That surgery is such a culture was well demonstrated in Charles Bosk’s study, *Forgive and Remember*,¹⁰ and Pear Katz’s *The Scalpel’s Edge: The Culture of Surgeons*.¹¹

Although surgery may be one of the last to the table, we may prove to be one of the most avid eaters. During the past several years one of the great institutions of surgical culture, The American College of Surgeons, has

increasingly addressed the issue of palliative care, commencing with a well-attended symposium chaired by Thomas Krizek on physician-assisted suicide held at the Clinical Congress of 1997.¹² Despite the differences of opinion concerning physician-assisted suicide, virtually everyone agreed to the value and utility of palliative care. Virtually everyone also agreed that surgeons were not well prepared cognitively or psychologically for this calling and the time had come to “do something” about it.

Shortly afterward, in February of 1998, the Board of Regents of the American College of Surgeons approved the *Statement of Principles of Care at End of Life* (see page-X-),¹³ which placed surgery in the company of many other medical specialties that had adopted similar statements.¹⁴ In the United Kingdom, where the precedent for palliative care was set, its precepts and techniques are already a part of the expected knowledge base of candidates for Fellowship in the Royal College of Surgeons.¹⁵

Recently, a group of surgeons from a variety of specialty backgrounds, with experience or strong interest in palliative care, has coalesced and has resolved to foster awareness, education, and research in these matters in conjunction with surgical institutions. The Surgical Palliative Care Workgroup had its initial meeting during the Clinical Congress of 2000 when its members presented a symposium, “Palliative Care by the Surgeon.” The Workgroup has recognized two important areas of endeavor: introduction to surgeons of information about end-of-life care and palliative care already available to other disciplines, and development of the concepts of palliative care in surgical procedures and practice. The Robert Wood Johnson Foundation has awarded a grant to fund the activity of the Workgroup, which plans to create a “White Paper” on palliative care in surgery in addition to continuing educational presentations.

The Workgroup will present a 3-hour symposium entitled, “Palliative Care by the Surgeon: How to Do It” at the ACS Clinical Congress in New Orleans, in October 2001. The Robert Wood Johnson Foundation has also awarded a grant to develop an end-of-life care curriculum for surgical residency programs. Members of the Workgroup are among the principal investigators along with Dr David Weissman, who has developed similar programs for internal medicine and family medicine. An initial pilot program comprising 30 residency training programs is planned.

The Workgroup planned this series of articles with the encouragement and assistance of the Editorial Board of this journal and Dr Olga Jonasson, representing the American College of Surgeons. The series intends to present, for consideration by readership, the precepts and salient problems encountered in palliative care occurring in a surgical setting. The succeeding articles are meant to be practical, informative, and to a certain degree, reinforcement of the most basic principles of this kind of care. Much of the background information for the series is derived from the EPEC curriculum (Education of Physicians on End-of-Life Care),¹⁶ which was developed by the American Medical Association and funded by a Robert Wood Johnson Foundation grant. The case-based format has been selected to remind us what has been learned in countless clinical encounters—the closer to the bedside, the better. We hope the articles will encourage interest and discussion among surgeons about situations of the human condition many of us would rather avoid, but where our input and our unique experience as surgeons is invaluable.

Appendix

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