



Guest Editorial

The Endless Challenges of End-of-Life Care

A good death = medical, psychological, spiritual support and free of pain

by David A. Fleming, MD

Death was not the enemy of ancient medicine. In fact, death was often welcome when patients were suffering and beyond hope.

Editor's note: David A. Fleming, MD, is Associate Professor of Medicine and Director, Center for Health Ethics, Department of Health Management and Informatics, University of Medicine School of Medicine, Columbia, Missouri. He has assembled a stellar panel of national experts in care of the dying patient and end-of-life issues. He has laboriously reviewed, edited, and coordinated their contributions into the first themed issues in Missouri Medicine's publishing history. The editorial board thanks Dr. Fleming for his efforts and expertise.

The barriers to successful end-of-life care result from misconceptions about death and dying, poor understanding about end-of-life care, what services are available, and reservations about using controlled substances. Because physicians are trained in a culture of cure, and because life-sustaining technology is so readily available, physicians are often reluctant to refer patients to palliative care programs or hospice because doing so may be viewed as abandonment.¹ In addition, resistance to using opioids and other controlled substances aggressively for dying patients may be influenced by a poor understanding about the use of these drugs, and fear of retribution from regulatory agencies. Physicians may also have strongly held personal beliefs about performing actions that may lead to premature death.² Patients expect to live longer and better lives in our society because of the expanding ability of modern medicine to cure disease and sustain life well beyond what might

otherwise be expected. The lifesaving orientation of modern medicine therefore tends to reinforce denial of death by both the patients and physicians.³

Death was not the enemy of ancient medicine. In fact, death was often welcome when patients were suffering and beyond hope. Modern drugs and technology have challenged the notion of futility by inserting a sense of obligation to combat death to the very end, because we can. Some argue that health care providers now have a "technological imperative" in the treatment of disease, which is to compulsively use technology to sustain life at all costs, even when palliative care would be more appropriate.⁴ As a result, research and education in the pathology, diagnosis, and treatment of disease has outdistanced parallel initiatives in the treatment of symptoms such as pain, dyspnea, depression, and fatigue, which are prominent contributors to the suffering of patients with terminal illness.⁵

For patients with cancer or other forms of terminal illness, prolonging life may also prolong suffering. The psychological and physical symptoms that accompany death can be severe, often dramatically affecting patients' will to live and their sense of autonomy.^{6, 7} Treatment for even the most severe forms of cancer pain is available and can be effective if done with an informed multidisciplinary approach.⁸ Surprisingly, up to one half of patients in programs devoted to palliative care still



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report significant pain one week before death.⁹ Studies indicate that physicians are often unaware of patients' preferences regarding treatment near the end-of-life and often fail to aggressively treat pain prior to death.¹⁰ Symptoms are poorly recognized and under-treated because physicians are often unaware or ill prepared to deal with the clinical circumstances surrounding death.

With increasing awareness and concern for these issues professional organizations and the public are now making care of the dying a national priority.^{11, 12} Multidisciplinary programs of palliative care are now available in most tertiary care medical centers. Health care providers with expertise and training in end-of-life care are also available for consultation in many community hospitals. Community hospice services are available in almost every county in Missouri. Yet, these services are still under utilized with one third of hospice patients dying within less than a week following admission.

A series of articles about end-of-life care is appearing in this and subsequent issues of *Missouri Medicine*. The first articles are offered as guidelines to assist health care providers who care for patients near the end-of-life. The topics have been selected to address some of major challenges confronted in end-of-life care and to provide information about a wide array of clinical, ethical, and legal issues. Steve Zweig, MD, offers a useful guide to hospice services in Missouri. The emphasis of this article is to provide answers to questions most commonly asked by physicians, underscoring the holistic nature of hospice, and reflecting on the family, social, cultural, and spiritual dimensions of dying. Clay Anderson, MD, provides a clinical guide to pain relief at the end-of-life. The problem of under-treatment is again emphasized. A useful discussion about the complex pathophysiology of pain is provided, followed by recommendations for the evaluation, management, and monitoring of patients who require pharmacological therapy.

I provide a discussion about the ethical and legal risks often encountered when treating pain. This article encourages good communication with the patient and other members of the health care team. I also emphasize good documentation of the patient's wishes, and the physician's intentions, both of which influence treatment decisions. The thesis of this article is that physicians are both ethically and legally accountable for their actions as health care professionals, but they should not be afraid to act according to the needs of the patient, even if that means the aggressive use of opioids or other controlled substances and withdrawing life sustaining treatment when indicated. Federal and state laws are in place to protect the patient and prevent abuse, but they also recognize that patients have a right to adequate pain control. Our prescribing habits should respond to those needs. Physicians should prepare themselves with appropriate knowledge and skill in the use of pain medication and other comfort measures, and refer to palliative care and hospice services when it is in the patient's best interest. Finally, an article by Scott Shannon, MD, and Paul Tatum, III, MD, provides an excellent discussion of the spiritual and psychological suffering that often accompanies severe illness. It is often this form of suffering that takes precedence for patients near the end-of-life and is most challenging for the physician.^{13, 14}

Dying is as natural as living, but accepting this reality can be challenging when there is always one more chance to cure. There are many patients for whom palliative care and hospice are appropriate, but diverting from a clinical attitude of "cure" to one primarily of "care" is often difficult. Optimal communication, good documentation, informed decision-making (by both the physician and patient), and fearlessness in the use of interventions that will relieve suffering

of all forms is the key to successful end-of-life care. Integrating these components for the benefit of the patient will be the endless challenge in the always-changing environment of health care.

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