

Bioethics for clinicians:

15. Quality end-of-life care



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Abstract

A PHYSICIAN WHO RECEIVES A CALL FROM THE EMERGENCY DEPARTMENT to see a patient with heart failure will have a clear framework within which to approach this problem. The thesis of this article is that physicians do not have an analogous conceptual framework for approaching end-of-life care. The authors present and describe a framework for end-of-life care with 3 main elements: control of pain and other symptoms, the use of life-sustaining treatments and support of those who are dying and their families. This 3-part framework can be used by clinicians at the bedside to focus their efforts in improving the quality of end-of-life care.

Résumé

UN MÉDECIN À QUI UN SERVICE D'URGENCE DEMANDE DE VENIR EXAMINER un patient en insuffisance cardiaque disposera d'un cadre clair pour aborder le problème. Dans cet article, on soutient que les médecins n'ont pas de cadre conceptuel analogue pour aborder les soins à la fin de la vie. Les auteurs présentent et décrivent un cadre de soins en fin de vie qui comporte trois éléments : contrôle de la douleur et des autres symptômes, utilisation de traitements de maintien de la vie et soutien aux mourants et aux membres de leur famille. Les cliniciens peuvent utiliser ce cadre à trois volets au chevet du patient pour concentrer leurs efforts afin d'améliorer la qualité des soins à la fin de la vie.

Dr. H is sitting at home enjoying dinner when the phone rings.* The caller is Mr. J, an acquaintance of Dr. H's. He is distraught. He asks how much air must be injected into an intravenous line to cause a person to die. When asked why he wants to know, he explains that his 72-year-old father, currently a patient in a local hospital, has end-stage metastatic lung cancer and is in excruciating pain. Mr. J cannot bear to see his father in such pain and wants to end his suffering by means of an air embolism.

Mr. K, a 68-year-old man with a 100 pack-year history of smoking and known chronic obstructive pulmonary disease, presents to the emergency department with pneumonia and respiratory failure. He has been intubated 4 times before for respiratory failure. He uses oxygen at home and is dyspneic at rest. He has hypoxemia and hypercapnia and is delirious. The emergency physician, Dr. L, tries to stabilize his condition with oxygen, salbutamol, steroids and noninvasive ventilation, but Mr. K's respiratory status worsens. Dr. L cannot locate Mr. K's family. She calls Mr. K's family physician and respirologist to find out whether they have ever discussed re-intubation, but unfortunately neither has done so. Although she is uncomfortable with this situation because of the uncertainty about the patient's wishes, Dr. L decides to perform the intubation.

What is end-of-life care?

A physician who receives a call from the emergency department to see a patient with heart failure will have a clear concept of what heart failure is, as well as a framework within which to approach the condition and its management. Our the-

*The cases in the Bioethics for Clinicians series reflect the authors' experience and are not intended to refer to any particular cases.

Education

Éducation

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sis in this paper is that physicians do not have an analogous conceptual framework for approaching end-of-life care. Several aspects of end-of-life care are addressed in other articles in this series, especially those on truth telling,¹ consent,² capacity,³ substitute decision-making,⁴ advance care planning,⁵ euthanasia and assisted suicide,⁶ and appropriate use of life-sustaining treatment.⁷ Our purpose here is to incorporate these pieces into a coherent conceptual framework that physicians can use to approach the care of patients at the end of life. Our framework, described in greater detail in the section “How should I approach end-of-life care in practice?,” has 3 main elements: control of pain and other symptoms, decisions on the use of life-sustaining treatment, and support of dying patients and their families. This article underlines the primary purpose of the “Bioethics for Clinicians” series: “to elucidate key concepts in bioethics and to help clinicians to integrate bioethical knowledge into daily practice. . . . [T]he goal is to support performance: what clinicians actually do.”⁸

Why is end-of-life care important?

Ethics and law

From an ethical perspective, the principle of beneficence requires that pain and other symptoms be controlled. The legal status of control of pain and other symptoms is not absolutely clear, but physicians should not risk legal peril if they follow established guidelines distinguishing these practices from euthanasia.⁹

Aspects of “life-sustaining treatment” comprise advance care planning, decisions to withhold or withdraw life-sustaining treatment and appropriate use of life-sustaining treatment. Advance care planning is ethically supported by the principle of respect for autonomy and is legally recognized in most Canadian provinces.⁵ Decisions by patients or substitute decision-makers to withhold or withdraw life-sustaining treatment proposed by a physician are supported by the ethical principle of respect for autonomy and the legal doctrine of informed consent.^{2,4} In contrast, the ethical and legal issues related to appropriate use of life-sustaining treatments demanded by patients and substitute decisions-makers over the objections of physicians are not as clear.⁷

Both euthanasia and assisted suicide are illegal in Canada.⁶

Policy

Recent policy initiatives have framed end-of-life care as an issue in health care quality — a positive development, in that it focuses organizational commitment to quality on the problem of end-of-life care. But what does quality end-of-

life care entail? In the United States, several organizations have published a “statement of principles” of quality end-of-life care that includes the following domains: treatment of physical and emotional symptoms, support of function and autonomy, advance care planning, aggressive care near death, patient and family satisfaction, global quality of life, family burden, survival time, provider continuity and skill, and bereavement.¹⁰ The Committee on Care at the End of Life of the US Institute of Medicine, National Academy of Sciences, has proposed the following 6 categories of quality end-of-life care: overall quality of life, physical well-being and functioning, psychosocial well-being and functioning, spiritual well-being, patient perception of care, and family well-being and perceptions.¹¹

Empirical studies

Although euthanasia consumes the attention of the media, the critical ethical issues vexing physicians, patients and families lie elsewhere. In particular, pain is often poorly managed.¹²⁻¹⁴ In one study of older patients who were conscious during the last 3 days of life, 4 in 10 had severe pain most of the time.¹⁵ In a survey of physicians and nurses at 5 US hospitals, 47% of respondents reported that they had acted against their conscience in providing care to the terminally ill, and 55% reported that they sometimes felt the treatments they offered patients were overly burdensome.¹⁶

Consistent with the recent focus of policy efforts, quality improvement strategies have been applied at the organizational level to the problem of end-of-life care.^{17,18} For example, in an innovative program called “Dialogue to Action,” Jacobson and associates¹⁹ arranged for the next of kin of patients who had died to describe their experiences of end-of-life care to members of the hospital ethics committee. It is likely that appropriate organizational change will require both the elicitation of “actionable reports” — narratives of care that highlight specific clinical areas for improvement — as well as the development of innovative ways to change clinical practice, for instance, by focusing traditional “morbidity and mortality rounds” on quality end-of-life care.

How should I approach end-of-life care in practice?

To address this question, we recommend a conceptual framework with 3 main elements: control of pain and other symptoms, decisions on the use of life-sustaining treatments, and support of dying patients and their families. We do not believe that a conceptual framework will magically solve the documented problems in end-of-life care; we do, however, believe that this is an important step.



Control of pain and other symptoms

No patient should die in pain or with other treatable symptoms. Indeed, before social, psychosocial and spiritual problems can be properly addressed, good symptom control must first be achieved: it is difficult to contemplate spiritual issues or to reflect on life's accomplishments when in pain or with kidney basin in hand. The under-treatment of pain and other symptoms is well documented, but aside from inadequate training of health professionals^{20,21} the causes are complicated and not well understood. On occasion, physicians may be concerned about balancing good symptom control with the risk of hastening death. Guidelines have been developed to assist physicians in distinguishing appropriate analgesia from euthanasia by lethal injection.⁹ Controlling other symptoms, such as nausea, fatigue and breathlessness, may be even more challenging than controlling pain, but effective approaches have been developed.²²

Physicians must keep in mind that the problems of dying patients have their genesis at an earlier time in the trajectory of illness. Thus, palliative care should not be isolated as simply an end-of-life option; it must be intermeshed with therapies aimed at prolongation of life or cure. As in other areas of medicine, prevention or early control of a symptom is preferable to a rescue attempt on preventable, but now out-of-control, suffering. Every physician who cares for

dying patients should ensure that he or she has adequate skills in this domain, as well as access to skilled consultative help from palliative care specialists. A list of leading journals and other information sources is given in the sidebar.

Use of life-sustaining treatments

To the extent possible, the patient and his or her family should be able to choose the site and nature of the care that the patient will receive in the last days of life and should be encouraged to discuss in advance their desires regarding life-sustaining treatments and personal care. Physicians should facilitate this advance care planning^{5,23-26} and guide and support the patient and the family through the process of giving consent to treatment and arranging for substitute decision-making.⁴ A key skill here is the communication of bad news.²⁷ In addition, physicians need to develop an approach to the opposite problem — when the patient or the family demands treatment that the physician feels is inappropriate.⁵ A key skill here is the ability to negotiate a treatment plan that is acceptable to the patient, the family and the health care team.²⁸

Support of patients and their families

The support that each patient and his or her family needs from the physician is unique. The best way to find

Resources for physicians providing end-of-life care

Comprehensive textbook

Doyle D, Hanks GWC, MacDonald N, editors. *Oxford textbook of palliative medicine*. 2nd ed. New York: Oxford University Press; 1998.

Palliative care manuals

MacDonald N, Boisvert M, Dudgeon D, Hagen N, editors. *Palliative medicine: a case-based manual*. Oxford: Oxford University Press; 1998.

Regnard C, Hockley J. *Flow diagrams in advanced cancer and other diseases*. London: Edward Arnold; 1995.

Twycross RG. *Symptom management in advanced cancer*. New York and Oxford: Radcliffe Medical Press; 1997.

Weller A, Caroline NL. *Handbook of palliative care in cancer*. Toronto: Butterworth-Heinemann; 1996.

Woodruff R. *Palliative medicine: symptomatic and supportive care for patients with advanced cancer and AIDS*. 2nd ed. Melbourne: Asperula; 1996.

Palliative care standards and policy statements

Canadian Palliative Care Association Stan-

dards Committee (Ferris FD, Cummings I, editors). *Palliative care: towards a consensus in standardized principles of practice* [first-phase working document]. Ottawa: Canadian Palliative Care Association; 1995.

Committee on Care at the End of Life, Division of Health Care Services, Institute of Medicine (Field MJ, Cassel CK, editors). *Approaching death. Improving care at the end of life*. Washington: National Academy Press; 1997.

Journals

European Journal of Palliative Care
Journal of Pain and Symptom Management
Journal of Palliative Care
Pain

Palliative Medicine
Psycho-Oncology (journal of the psychological, social and behavioural dimensions of cancer)
Supportive Care in Cancer (official journal of the Multinational Association of Supportive Care in Cancer)

World Wide Web sites

www.ama-assn.org/EPEC
American Medical Association Education for Physicians on End of Life Care

oris.microtec.net/~AQSP

Association québécoise des soins palliatifs

www.islandnet.com/deathnet
DeathNET

www.palliative.org
Edmonton Palliative Care Group

www.gwu.edu/~cicd
George Washington University Center to Improve Care of the Dying

www.multi-med.com/oncology/oncopain
Oncopain, a forum on pain management open to health care professionals only

www.soros.org/death.html
Open Society Institute Project on Death in America

lastacts.rwjf.org/default_home.htm
Robert Wood Johnson Foundation Last Acts Campaign

www.pallcare.org
University of Ottawa Institute of Palliative Care

www.utoronto.ca/jcb
University of Toronto Joint Centre for Bioethics (includes the full-text version of the centre's living will and links to other end-of-life Web sites)



out what support will be appropriate in a particular situation is to ask, "How can I help you?"

Attention to psychosocial issues demands involvement of the patients and their families as partners. Although physicians should be sensitive to the range of psychosocial distress and social disruption common to dying patients and their families, they may not be as available or as skilled as nurses, social workers and other health care professionals in addressing certain issues. An interdisciplinary health care team can help in these areas.

Spiritual issues often come to the fore as one is dying, and pastoral care teams should be available to assist the patient's own clergy in counselling.

Although not all families need or desire follow-up after the death of a loved one, many appreciate a letter or a telephone call from the physician or a member of the palliative care team. Some families will need more specific help. Physicians should be sensitive to risk factors for poor adjustment to bereavement and should be knowledgeable about local bereavement services.²⁹

The cases

Both of the cases presented at the beginning of this article represent failures in end-of-life care. In the first, inadequate pain control led to a desire for euthanasia. What was needed was not an air embolism but better pain control. When this was achieved, Mr. J was relieved and did not pursue the idea of euthanasia. This case also illustrates that physicians should not take requests for euthanasia at face value; rather, they should explore and address the problems in end-of-life care that might have led to such requests.

The second case represents a failure of communication about life-sustaining treatments. Mr. K had end-stage lung disease and had been intubated 4 times previously, so he was ideally situated to know whether he wanted to undergo the procedure again; indeed, it is very likely that he had considered this possibility. If he did want intubation, knowledge of his wishes would have relieved Dr. L's anxiety. (Although death was looming, it would be difficult to claim that intubation would be futile in this case, given that it had worked before.) If Mr. K did not want to undergo intubation, he missed his opportunity to communicate this desire. Arguably, the family physician and the respirologist should have broached this issue with him and helped him to make his wishes known in such a way that they would be effectively communicated when respiratory failure occurred.

In summary, physicians caring for patients at the end of their lives should ask themselves 3 questions: Am I managing this patient's pain and other symptoms adequately? Have I addressed the relevant issues with respect to the use of life-sustaining treatment? Am I supporting this person and his or her family?

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