

Care at the End of Life: Guiding Practice Where There Are No Easy Answers

Throughout the ages, people have sought a “good death” in which they are physically as comfortable as possible, are treated with compassion and respect, and find closure in their lives. In the United States at the end of the 20th century, this quest remains elusive. Many people fear that they will have unrelieved symptoms, will undergo unwanted life-prolonging interventions, or will be abandoned by their health care providers.

This editorial announces a new series of articles on end-of-life care in *Annals* whose goal is to provide practical advice and other guidance to clinicians who are not specialists in palliative care and for whom the care of dying patients is not an everyday aspect of their practice. These papers supplement the ethics and policy positions articulated in the fourth edition of American College of Physicians *Ethics Manual* (1).

Recent research documents serious problems in medical care at the end of life. Many patients suffer significant pain in their final days (2, 3). Physicians commonly do not know their patients' preferences for life-sustaining interventions or fail to carry out those preferences (2). Communication often is poor; many seriously ill patients and physicians do not discuss care at the end of life (3). When conversations do occur, physicians miss opportunities to address patients' concerns and fears (4). Relatives of patients have written eloquently of the problems they encountered with the care of a dying patient (5).

Improving care at the end of life is particularly important in light of ongoing public discussions about managed care and physician-assisted suicide. Appropriate palliative care may be as costly as disease-oriented care (6). Some people fear that capitated reimbursement creates an incentive to restrict appropriate care at the end of life in order to save money (7).

Physician-assisted suicide has generated tremendous controversy. Some public support for physician-assisted suicide results in part from fears of unrelieved suffering and loss of control over care at the end of life. Physicians, regardless of their views on physician-assisted suicide, can agree that excellent palliative care will probably diminish interest in physician-assisted suicide.

Control of symptoms, relief of distress, promot-

ing quality of life, and attending to the psychosocial aspects of illness are appropriate in all stages of disease, including early on, when interventions are directed against the underlying pathophysiology (1). When patients with cancer undergo curative treatment, the side effects of chemotherapy need to be relieved and psychosocial issues of coping with disease and treatment should be addressed. These patients may have considerable pain even early in their disease, yet physicians often withhold opioids at that time (2, 8). Discussions can be put into the context of exploring patient and family concerns about the future, helping the patient be in control of care, and establishing shared goals for care.

Palliative care is commonly considered terminal care, separate from and mutually exclusive with treatments that cure the underlying disease or treat the underlying pathophysiology (9). In this view, there is a sharp transition from disease-oriented therapy to palliative care. Hospice, the most familiar system for providing palliative care in the United States, is often considered only in the final stage of disease. The average patient enters hospice 1 month before death, and 16% enter only 1 week before death (10). This approach stems largely from how hospice has historically developed as a Medicare benefit. Under Medicare, physicians must certify that patients are expected to survive less than 6 months (11). This requirement, together with inherent uncertainties in prognostication, may lead physicians to refer patients to hospice very late in their disease. In addition, hospice requires patients to accept a limited prognosis and perhaps “give up” treatment for their underlying disease.

Serious problems result when palliative care is considered only after disease-oriented care fails or becomes too burdensome or when the patient reaches a clearly defined terminal phase. Opportunities to relieve symptoms and achieve meaningful closure to life may be missed. The negative perception that palliative care means that all else has failed is reinforced. Patients may infer incorrectly that relieving symptoms is important only near the end of life. Furthermore, it is difficult to identify patients who are expected to die in the very near future, particularly in diseases other than cancer. For instance, patients with congestive heart failure

typically die of sudden arrhythmia and do not have a predictable terminal phase of progressive decline (12). Thus, discussing palliative care only with patients who are highly likely to die soon will miss many patients who may benefit from it.

To avoid these problems, physicians should take a “both/and” approach to palliative and disease-oriented care instead of an “either/or” approach. Palliative care should be regarded as coexisting with disease-oriented therapy throughout a patient’s care rather than as a sharp transition before death (9, 11). As disease progresses, many patients may decide to forgo some disease-oriented therapies, and relief of symptoms and attention to psychosocial needs may require increased attention. However, even if comfort becomes the primary goal of care, some disease-oriented therapies may be continued or initiated. For example, local radiation therapy may be the most effective approach to relieve symptoms caused by a metastatic cancer lesion. Palliative care at the end of life is not equivalent to low-technology care at home.

To provide better palliative care, physicians need to improve several skills. First, they need to provide better relief of physical symptoms. Although inadequate pain control has received the most attention, other symptoms, such as dyspnea and delirium, are common and distressing (13). The most recent edition of the *Oxford Textbook of Palliative Care* presents up-to-date information on the knowledge base of palliative care (13, 14). Second, physicians need to improve decision making about life-sustaining interventions. Patients or their surrogates should be involved in decisions if they wish to do so, and their preferences and values need to be better taken into account. Third, physicians need to improve their discussions with patients and families about end-of-life care. Such conversations are never easy because sadness, grief, and fear of the unknown are inevitable. Fourth, clinicians must address practical issues in clinical management, such as how to respond to disagreements among staff members and families, the constraints of institutional policies, or misconceptions about the clinical effects and ethics of high-dose narcotics for symptom relief. Fifth, good end-of-life care can help dying patients achieve closure and find meaning in the final phase of their lives (15).

Members of American College of Physicians–American Society of Internal Medicine (ACP–ASIM)—both general internists and subspecialists, particularly in oncology, geriatrics, and critical care medicine—provide a great deal of care to dying patients. The ACP–ASIM End-of-Life Care Consensus Panel, consisting of experts in end-of-life care, was convened in 1997 to provide assistance in improving care. The Greenwall Foundation has supported this project. The goal was to identify clinical,

ethical, and public policy problems in end-of-life care where improvement was desirable, to critically analyze the available evidence and guidelines, and to offer consensus recommendations on how to better address these problems.

A series of papers on communication about palliative care; care of patients with dementia; the goals of palliative care; pain management in cancer; palliative care in the intensive care unit; terminal suffering; management of depression at the end of life; and legal, financing, and cultural issues are being authored by members of the ACP–ASIM End-of-Life Care Consensus Panel. Papers are debated by the panel and are subjected to peer review. This process includes review by other experts in end-of-life care and by experienced clinicians. All of the papers were reviewed by ACP–ASIM’s Ethics and Human Rights Committee, the Education Committee, the Board of Governors, and the Board of Regents. Articles that are accepted by *Annals* will appear in the next year or so.

Many papers will use a case-based approach. Discussions of cases, which are a traditional teaching format in medicine, can stimulate the interest of readers who have puzzled over similar situations. A rich case discussion that highlights management questions provides indirect experience in problem solving. The reader can consider how to approach a problem, how to tailor decisions to an individual patient, and how to address such practical constraints as time and staffing (16). Case analyses lend themselves to use in conferences and seminars in hospitals, residency programs, professional meetings, and continuing medical education courses.

As an organization, ACP–ASIM is committed to improving the quality of care at the end of life. These papers are intended to help physicians integrate excellent end-of-life care into the everyday practice of internal medicine.

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Ann Intern Med. 1999;130:772-774.

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The Making and Unmaking of a Journal

Much has been made of the recent firing of George Lundberg, the editor of the *Journal of the American Medical Association (JAMA)* for 17 years. We've heard about timing the publication of papers on "hot" topics, the seeking of media attention, the intrusion of political agendas into scientific journal publishing. We've reacted strongly to strong personalities, puzzled over who should hire and fire journal editors, and rethought the principle of editorial freedom that underlies it all (1–5). What's gotten lost in all the shouting about personalities and principles, unfortunately, is the pragmatic issue of how hard it is to build a journal, and how easy it is to destroy one.

Putting out a biomedical journal is almost as much a performing art as an intellectual exercise, and an enormously complex one at that. Journals are needed because "one of the strictures of the scientific ethos is that a discovery does not exist until it is safely reviewed and in print" (6). But getting those discoveries safely reviewed and into print in a major journal depends directly on a very large cast of characters: a few editors; some highly sophisticated statisticians; a great many more production and support staff (nowadays including some with high-level expertise in electronic information systems); peer reviewers by the thousands; advertisers by the dozen; an editorial board; and a sponsoring organization, which is usually also the journal's publisher. A vigorous journal of course needs a dedicated readership, and these days a journal also connects in important ways with an ever-expanding

array of interested parties, including industry, foundations, government agencies, the media, and the general public.

As in the performing arts, the success of a journal depends on the actions and interactions of many individual players, linked together dynamically in circles of causality, what Peter Senge calls reinforcing feedback loops (7). Thus, for example, the publication of good papers attracts better papers; better papers mean that reviewers are more willing to review; stronger reviews further increase quality, leading to greater journal utility and credibility, hence more readers. Increased readership then generates more subscription revenue and attracts more authors and more advertisers, hence more resources to build quality (not to mention resulting in a more satisfied publisher); and the "boom" continues. The problem is that the dynamic state of journal life, which is the source of journals' vigor and growth, is also what makes them vulnerable. Once something goes seriously wrong at a critical point in the system, the entire operation can rapidly unravel: Positive cycles can become vicious ones, and even a strong journal can rapidly spin off into a "death spiral." An old adage, "You're only as good as your last performance," captures very well the fragility of life in the theater; it applies to journals, too.

The performing arts have their patrons who control much of their destiny; biomedical journals have their sponsors—professional societies in most cases, commercial publishers in a few. And thereby hangs the tale, since medicine, even at its scientific best, is

always a social act (8). Biomedical journals therefore feel a responsibility to speak out on the social, economic, and political issues that increasingly bear on medical practice. Sometimes, unfortunately, sponsors' agendas work at cross purposes to those of their journals, as appears to have been the case with the American Medical Association and *JAMA* under George Lundberg. In such situations, editorial freedom is important in the same way free speech is important generally: as a bedrock principle in public life. But editorial freedom is important for journals in another, more pragmatic, way: as protection for the living institution, the intricate web of people, relationships, and credibility that is a journal. Weaving that web takes years of painstaking work; repairs, once it has been torn apart, may be difficult, if not impossible.

It is too soon to know the extent of the damage to *JAMA* from the precipitous and unceremonious firing of its editor. Its staff and editorial board have made valiant efforts at damage control (9); the American Medical Association is making reassuring noises; and the search committee for the new editor is going back to square one in an attempt to rebuild the journal's credibility and integrity (10). But the injury is a grievous one, and the damage could be long-lasting.

Biomedical journals matter because biomedical science literally doesn't exist without them. *JAMA* matters because it has put together the people and the credibility that serve medicine well. We all lose if those are lost.

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Editor

Ann Intern Med. 1999;130:774-775.

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