Economics, Ethics, and End-of-Life Care

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Pressure to reduce total health care expenditures in the United States has intensified. Despite a contracting health care budget that has sensitized society to the issues of resource allocation, the demand for the health care dollar has continued to expand. The disciplines of economics and bioethics have each outlined strategies to mitigate this conflict. Yet because of divergent core preferences, the proposed strategies are discordant. Whereas economics is chiefly concerned with the quantitative analysis of the production, distribution, and consumption of goods and services—an approach that often creates value-loaded trade-offs—bioethics often addresses the variance among competing values without accounting for resource scarcity. 1 When the overall priority is to decrease monetary costs, selecting the most desirable way to allocate resources depends on which values are assumed to be paramount. 2 If we are to develop morally acceptable principles for allocating scarce resources, the two approaches must reach a concordance.

Decisions regarding the delivery of health care at the end of life underscore the inherent conflict between economics and bioethics. Many argue that because 10% to 12% of all health care expenditures and 27% of Medicare expenditures are spent at the end of life, 3 and because these expenditures frequently fail to provide significant health benefits, the elimination of such care would make resources available for other unmet needs. Opponents counter that cost savings projected from reduced care at the end of life are illusory, 4 and that such reductions in care breach the maxim that the least advantaged should be accorded maximum benefit from an unequal distribution of any primary good. 5 Rationing itself is not denounced as ethically unacceptable, so long as the deprivation of goods is egalitarian. This attitude contrasts with British National Health Service guidelines that explicitly refuse more broadly, and pursue constructs outside the biological sciences.

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Health care faces 2 large problems that will in the future force consideration of some difficult questions about the nature of medicine and health care. The first concerns “marginal benefits,” which affect the care of all patients. How shall we manage and allocate the growing number of expensive treatments and pharmaceuticals that provide only limited benefits? The second problem concerns health care for the elderly and the financial crisis the federal Medicare program is expected to undergo as the baby boom generation retires. These 2 issues are connected because health care for the elderly, particularly those over age 85, is marginal in the sense that life expectancy is relatively short thereafter, even if a particular intervention is successful by a particular standard.

A number of proposals in recent years have attempted to deal with this dual problem. One proposal argues for increasing and improving outcome assessment and evidence-based medicine to better determine what is and is not beneficial to patients. This approach, however, does not resolve ethical dilemmas over health care allocation, such as whether to spend money on expensive treatments with a low probability of succeeding (eg, bone marrow transplants). Another proposal is to reduce the notoriously high costs of end-of-life care by a combination of outcome assessment studies and an expanded and improved use of hospice programs and advance directives.

The key issue for the future is whether this society will continue its present course of using more marginally beneficial technologies to improve health care for the elderly—refusing, in effect, to accept the historical decline in health associated with aging—or whether society will take a population-based approach by putting more resources into improving health in younger years and thus increasing the likelihood of better health in later years. Examples of the latter might include working with health promotion and disease prevention programs to reduce illness and disability prior to death.

Only the latter course seems based in common sense. Trying to cope with the inevitably expanding health needs of the elderly by means of ever more expensive technologies with marginal health benefits to the population as a whole makes little economic sense. Conversely, to think that we can manage growing costs through cost reductions at the end of life and greater application of evidence-based medicine is far too optimistic.

My pessimism regarding the possibility of achieving a technical correction through outcome assessment studies runs counter to prevailing sentiments within US medicine. One reason for this pessimism is that the pharmaceutical and medical manufacturing industries are endlessly adept at developing new technologies, hardly any of them curative and most of them expensive. US physicians, with the eager support of their patients and sometimes the reluctant assent of HMOs, are ready to adopt these technologies. War has been declared against death and its historical ally, aging.

Are there any means to make a population health perspective more attractive to society? Three attitudinal changes would have to occur. First, there must be, at some point, a limit on the amount of money deemed worth spending on marginal medical improvements—a point where the price is too high for too little return. The second is to persuade the public that a population-based approach appears to produce not simply a less expensive way of dealing with health and illness, but overall improved health for most, though not all, individuals. The third change is the most radical, at least for this culture. We must accept old age and death as part of the course of human life and settle for the more modest goal of a decent average life expectancy of, say, 80 years and a good quality of life before that point.

In the search for a biological map, which many would call “reductionist,” to better health in the future, current research emphasizes the genetic roots of disease. Although this may be a scientifically sound research strategy, it is not clear that it will result in more affordable medicine in the future. A population health strategy could, conceivably, produce comparable success at a more affordable price. Some marginal benefits might be lost, additional people might die, and others might have a lessened quality of life. But we could have a more realistic and economically sustainable kind of health care: in my view, a splendid trade-off.

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### 2000 John Conley Ethics Essay Contest for Medical Students
Information about the contest can be found online at http://www.ama-assn.org/sci-pubs/msjama/index.htm.
PEOPLE ARE LIVING LONGER WITH FEWER DISABILITIES.\textsuperscript{1} Technological changes are partly responsible for this phenomenon, yet new technology is often costly, and many interventions at the end of life seem wasteful. Given rising health care costs and projected Medicare deficits, end-of-life care is a possible target for expenditure reduction.\textsuperscript{2} If such expenditures are limited, there might be decreased pressure to restrict other health care spending. Alternatively, end-of-life savings could go toward expanding Medicare benefits, such as those covering prescription drugs.

Much discussion about end-of-life care focuses on private interactions among patients, caregivers, and physicians. Because of financial incentives, lack of knowledge, or poor communication with patients and families, physicians may not make appropriate care decisions. Even if such decisions reflect patient and family preferences, viewed from a collective perspective, there may be better ways to deploy resources currently spent on end-of-life care.

Given the social norm to honor patient and family preferences concerning end-of-life care, many issues remain unresolved. Theoretically, decisions regarding preferred care may be clear, but practically those decisions only come after the fact. Many patients fear the dying process and the burden on their families even more than death itself.\textsuperscript{3} Patients' levels of consciousness and ability to communicate during the 3 days before death vary by medical condition.\textsuperscript{3,4}

In addition, little is known about patients' and families' preferences for care at the end of life. Do care preferences remain stable, or do they depend on where one is on the life spectrum? How often do the preferences of patients and family members differ,\textsuperscript{4} and how are such differences resolved? How well informed are persons involved about treatment options, especially for palliative care administered near the end of life?

Although there is a positive correlation between the care preferences of patients and their physicians, there is much to be learned about interactions between patients, caregivers, and physicians.\textsuperscript{5} Lack of knowledge among physicians about treatment options and legal and regulatory requirements, such as regulations on pain-prescribing practices, may impede provision of appropriate care.\textsuperscript{6} Hospital payment policies favoring rapid discharge may discourage physicians from providing palliative care. The relative importance of these factors in the larger picture of end-of-life care is unknown.

Impending death is an important predictor of health care spending,\textsuperscript{7} but this effect is smaller for the oldest people approaching death and greater for those younger. This suggests the advisability of a pattern of less aggressive care when the possibility of life extension and quality of life enhancement lessens, but no study to date has quantified the amount of nonbeneficial care actually provided to persons near death.

The role of insurance is complex. When Medicare and other insurers cover end-of-life care, more such care will be demanded, both beneficial and nonbeneficial. Much of the beneficial care is likely to be supportive. If not financed by insurers, the cost of such care is borne by families. The public policy issue here is not whether such care will be provided, but who should pay. Should cost be spread among members of society or borne by families? Chronic and terminal illnesses have substantial financial consequences on families.\textsuperscript{8} Unlike other unequally distributed hazards, such as house fires or car thefts, we all face death, implying that some collective judgments about such care are appropriate. The guidelines should partly depend on effectiveness parameters, but there is also the normative issue of how much good outcomes are worth, and how this calculus is modified by age. Such guidelines will be hard to develop since much aggressive care will appear to have been nonbeneficial only after death; the perspective is often quite different earlier.

Resources not devoted to health care may satisfy other societal objectives. The percent of health care cost attributable to end-of-life care has been remarkably stable over time.\textsuperscript{7} Projected savings from greater use of advance directives, hospice care, and less aggressive treatments have been estimated at 3.3\% for total health care and 6.1\% for Medicare spending.\textsuperscript{2} These reductions are programmatic and exclude increases in the cost of care borne by families. At current rates of increase, a 6.1\% reduction would offset 1 to 2 years' increase in Medicare program costs, a very partial antidote to forecasted Medicare deficits.

Policies to improve the provision of end-of-life care would only offer minimal promise for cost containment. Greater savings could undoubtedly be achieved by imposing severe budgetary or capacity constraints on the financing and provision of care.\textsuperscript{2} But, a focus on rationing care for persons at the end of life would be widely viewed as inequitable.

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US residents do not have a legal right to the care that they would like to have at the end of life. They do not have the legal right to demand expensive life-extending care, despite limited prospects of success; nor do they have the legal right to expect even minimal comfort care. In the United States there exists no general legal right to end-of-life care, extensive or minimal, just as there is no general legal right to health care. There are exceptions to these assertions; specific groups such as the elderly, the disabled, the poor, the imprisoned, or those with end-stage renal disease, may, because of their legal status or health condition, have been granted limited rights to health care. The right to health care at the end of life is thus a complex picture, and addressing the issue comprehensively requires a basic understanding of the nature of rights and the structure of a federalist legal system.

Rights may be either positive or negative. A positive, or welfare, right would be the right to actually receive care. A negative right, or right of noninterference, would be the right not to encounter barriers in seeking care. Unlike most other advanced industrialized nations, the United States does not have a tradition of legally recognizing general welfare rights. Positive rights, therefore, exist only within limited circumstances.

Although the US Constitution does not grant any general welfare rights, there is one health care exception. Prisoners have the right under the 8th Amendment not to be subjected to cruel and unusual punishment; this right is violated when incarcerated people do not receive adequate health care.

Federal statutes extend some additional positive rights in the health care arena. Individuals over the age of 65 who qualify for Social Security, permanently disabled persons, and those with end-stage renal disease are entitled to Medicare funding. But Medicare has coverage limitations. It does not cover experimental care or care that is not deemed reasonably medically necessary. New life-extending therapies, such as autologous stem cell transplants for multiple myeloma, may not be covered by Medicare. Medicaid, a federal program that extends health care dollars to state programs for the poor, also provides some coverage for end-of-life care. Approximately 30% of Medicaid funds are spent on care for the impoverished elderly, although only 11.9% of Medicaid recipients are over age 65. In addition, the Emergency Medical Treatment and Active Labor Act (EMTALA) is a federal statute that was enacted to prevent patient dumping. EMTALA requires facilities receiving federal funds and operating an emergency department to provide appropriate medical screening examinations and temporary and necessary stabilizing care. In some circumstances, courts have held that the stabilizing care required may be quite extensive, but it does not extend to longer-term modes of care, such as chemotherapy.

The US Constitution assures negative rights of nondiscrimination and of liberty that are relevant to health care. The 14th Amendment prohibits states from depriving citizens of equal legal protection. Therefore, state institutions or agencies may not discriminate in providing end-of-life care on the basis of race, nor can they ration care in a manner that fails equal protection scrutiny.

Several recent decisions of the US Supreme Court have explored the protection of patient liberties under the 14th Amendment’s due process clause. The decision in Cruzan v Director, Missouri Department of Health assumed that competent patients have the right to refuse care and indicated that states may not unduly burden patients’ efforts to extend that liberty through advanced-care planning. In Compassion in Dying v Washington, the Supreme Court refused to extend constitutionally protected liberty to aid in dying. Several justices did nonetheless suggest that they would extend protection to adequate palliative care.

Within limits set by the US Constitution or federal statutes, states also may extend legal protection to citizens’ liberty to seek out end-of-life care. States may also extend some rights to care itself through mandated benefits, state medical emergency funds, or state analogs to EMTALA. State constitutions or statutes may protect more extensive liberty rights or antidiscrimination rights than the federal constitution. For example, state intractable-pain statutes protect physicians who follow medically acceptable forms of aggressive pain management. Perhaps the most controversial state initiative is Oregon Measure 16, which protects physicians who write prescriptions intended for aid in dying, in accord with prescribed safeguards.

Thus in the United States today, rights to end-of-life care are limited and highly variable. A patient may have a status such as imprisonment, a condition such as end-stage renal disease, or a state residency that brings with it legal claims to care. More likely, a patient will only receive legal protection preventing interference with the health care that she or he is otherwise fortunate enough to be able to access.
Medical Students’ Attitudes Toward Physician-Assisted Suicide

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Context In November 1994, Oregon became the first US state to legalize physician-assisted suicide (PAS) as an option for end-of-life care.

Objective This study compares the attitudes and experiences of medical students in Oregon regarding PAS to those of fourth-year medical students in the United States outside Oregon.

Design A survey of all students at the Oregon Health Sciences University and fourth-year medical students at 3 non-Oregonian US medical schools.

Participants Oregon medical students returned 227 questionnaires (58%), and 113 were returned from control schools (33%).

Results A similar percentage of both study groups favored the legalization of PAS (64% vs 65%; \( P = .74 \)). If the practice were legal, 55% of the total surveyed reported they “might be willing to write a lethal prescription,” (50% Oregon students vs 60% control; \( P = .13 \) and 44% fourth-year Oregon students vs 60% control; \( P = .04 \)). Among fourth-year students, 20% reported a request by a patient to the student or a preceptor for a lethal prescription in the past year (26% vs 16%; \( P = .09 \)).

Conclusions This study demonstrates support for and willingness by many medical students to participate in PAS. Some medical students reported observation of PAS during their training experience. Fourth-year Oregon students reported significantly less willingness than other students to provide a patient with a lethal prescription, perhaps indicating hesitancy to include PAS in clinical practice.

In 1994, Oregon became the first state to legalize physician-assisted suicide (PAS) with passage of the Oregon Death With Dignity Act1 and today remains the only US state in which PAS is legal. To assess the attitudes of Oregon physicians toward euthanasia and PAS, a questionnaire was developed by the Oregon Health Sciences University (OHSU) Center for Ethics in Health Care and sent to Oregon physicians in 1995.2 Results of this study demonstrated widespread support for the law, and since its passage many physicians have participated in PAS.3 Additional studies have consistently demonstrated that a large percentage of physicians support PAS.4-10 Most US medical schools now specifically address end-of-life care in their planned curriculum, and several organizations are developing and disseminating physician education programs to improve end-of-life care.

The current study compares the attitudes and experiences of Oregon medical students regarding PAS to a sample of non-Oregon US medical students. Additionally, fourth-year Oregon students were compared to first-, second-, and third-year Oregon students with less clinical experience. These comparisons demonstrate differences in attitudes that may exist between students who face a real possibility of providing PAS in the immediate future and students for whom PAS is less likely to be an issue in practice or is less commonly addressed in clinical experience.

METHODS

Study Design

All students at the Oregon Health Sciences University, the only school of medicine in Oregon, received a previously developed, anonymous 54-item questionnaire2 in their campus mailbox. The same questionnaire was sent to fourth-year medical students at 3 other medical schools chosen through a stratified randomization process, 1 each from the midwestern, southeastern, and northeastern regions of the United States. This study design was chosen to compare the attitudes and experiences of students in a state in which PAS is legal to those of students in states in which PAS is not legal. Questionnaires were returned in provided, self-addressed, stamped envelopes. No incentive was offered for participation. OHSU students were given 3 formal, written reminders to increase response rate. Students at the control schools received only the initial envelope.

Survey Instrument

The questions included in this student questionnaire were similar to those in the original questionnaire2 and assessed basic demographic information, general attitudes toward PAS, and actual clinical experience with PAS issues. Two questions from the original questionnaire were excluded because they applied only to practicing physicians; several questions were edited to address students more appropriately. The OHSU Human Subjects Committee and the original questionnaire’s authors approved the revised questionnaire.

Subjects

Participating schools approved student participation. Confidentiality was ensured by the use of an anonymous questionnaire returned in a sealed envelope. As envelopes arrived at the collection office, the signed consent form and questionnaire were immediately separated, and student participation was tracked by crossing each student’s name off a class list using the signed consent form. The database therefore contained no markers identifying students.

Statistical Analysis

Data were analyzed using SPSS (Version 6.1, SPSS, Inc). Three study groups were identified: control students; OHSU fourth-year students; and OHSU first-, second-, and third-year students. Comparisons were all Oregon students vs non-Oregon students; fourth-year Oregon students vs controls; and fourth-year Oregon students vs first-, second-, and third-year Oregon students.
year Oregon students. Continuous variables were analyzed using t tests and categorical variables were analyzed with the χ² test. Correction for multiple comparisons was not used.

RESULTS

Sample Characteristics

Of the 399 questionnaires administered to Oregon students, 227 were returned (58%). Of the 340 questionnaires administered to control students, 113 were returned (33%). The final study group consisted of 51% male students with a median age of 28. All groups were similar in gender, specialty preference, religion, or experience in caring for terminally ill patients, but fourth-year Oregon students, compared to controls and first- through third-year Oregon students, were older and less likely to have attended high school in a large city (P = .02; P = .005). Compared to the control students, the combined group of Oregon students was younger (P<.001), more likely to project entering primary care (P = .03), less likely to report any religious affiliation (P<.001), and reported less experience caring for terminally ill patients (P<.001).

Outcomes

Oregon and non-Oregon students were equally likely to find that PAS should be legal in some situations (P = .74) and if legal, 52% of students from Oregon (52% vs 60%) reported that they “might be willing to assist a patient by writing a lethal prescription.” Fourth-year Oregon students were significantly less likely than non-Oregon fourth years to report a willingness to provide a patient with a lethal prescription (44% vs 60%; P = .04) and were also less likely to report this willingness than other Oregon students in earlier stages of medical school (44% vs 55%; P = .14).

More Oregon fourth-year students (26% vs 16%) reported a request by a patient in the previous year to themselves or their immediate preceptor for a lethal prescription (P = .09). Students from Oregon were equally as likely as controls to comply with these requests (P = .93).

DISCUSSION

In this small sample, a large percentage of US medical students feel that PAS should be legal and report willingness to practice PAS, if it were legalized. Previous administration of this survey to Oregon physicians demonstrated that 60% felt that PAS should be legal in some cases, and more similar to the 65% found for all medical students in this study. Interestingly, the group least willing to write a lethal prescription was fourth-year Oregon medical students (44%). This result is similar to that previously found for practicing Oregon physicians (46%) and much lower than this study’s results for non-Oregon fourth-year medical students (60%) and younger Oregon students (55%). Nationwide, 36% of physicians would be willing to write a lethal prescription. This significant difference between fourth-year Oregon students and the other study groups may indicate that a change in willingness to comply occurs when a person is faced with actually writing lethal prescriptions. In addition, the “end-of-life” curriculum for Oregon students includes added emphasis on alternative approaches to end-of-life care, perhaps leading fourth-year Oregon students to believe that compliance with a request for PAS could be unnecessary.

Regarding requests for lethal prescriptions, 18% of physicians nationally and 21% of Oregon physicians have received such a request. These findings are similar to the 20% of fourth-year students in this sample reporting such a request, to either themselves or their immediate preceptor. Compliance with a request was observed by 6% of fourth-year medical students (of those reporting a request), comparable to the 7% among Oregon physicians (before passage of the ballot measure) and lower than the 16% found nationally. The finding that a similar percentage of US physicians receive requests for lethal prescriptions may be an indicator of similarity in the quality of end-of-life care provided throughout the United States or of similarity in patients’ attitudes toward this option.

Limitations of this study include a low return rate and return bias. Return bias could have resulted because participating schools restricted the issuance of reminders. These restrictions also made it difficult to assess the number of students who actually received the survey. Because of the low response rate of the controls, these results might not be representative. Nonetheless, this study provides insight into the attitudes of some medical students toward PAS. More than 60% of medical students surveyed feel that PAS should be legal in some situations and comment that they would be willing to participate in this practice if it were legal.

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