

Ethics Perspectives on End-of-life Care

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Aggressive medical management of the terminally ill has given rise to significant issues in the ethics of end-of-life care. The major ethics principles of autonomy, beneficence, and justice help frame existing research findings. A wave of national initiatives to improve end-of-life care is occurring.

Technologic advancements in aggressive medical management at the end of life now have led more Americans to fear *how* they die than death itself. The lay popular press¹⁻⁴ reflects how widespread is public dissatisfaction about health care system management of dying in the United States. Surveys⁵ indicate that if given the choice, most Americans would avoid aggressive intensive care unit (ICU) care if the short-term outcome is likely to be death. The widely disseminated findings from SUPPORT,⁶ the single largest and most comprehensive study of hospital-based dying, and the recently released Institute of Medicine report, *Approaching Death*,⁷ combine to set the stage for major reforms in end-of-life care.

A majority of Americans die in acute treatment hospital settings,⁸ and most in-hospital deaths are “negotiated” (ie, the deaths follow a period of decision making between the patients’ family and the clinical team about how much aggressive treatment to try and when to shift from the goal of recovery to the goal of comfort). The result of such negotiated trials often is an overly long period of aggressive treatments, which are burdensome to the patient, exhausting and expensive to the family, demoralizing to clinicians, and difficult to justify for society’s resources.⁹ Many experts think it is this type of burdensome dying that has fueled public demand for physician-assisted suicide. Certainly, this profile of dying invites reflection about ethics issues in end-of-life care. From the perspective of each of the 3 key ethics principles—autonomy, beneficence, and justice—research findings help inform the state of the science and set the context in which a wave of new initiatives occur aimed at improving end-of-life care.

PRINCIPLE OF AUTONOMY: PATIENT’S VOICE

Western health care systems have long regarded autonomy as the dominant ethics principle in directing clinical decisions.

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Major advances in patient autonomy have been made in affirming the moral and legal right of mentally competent patients to make decisions about the course of their dying, in improving the methods for the expression of patients’ preferences, and in better understanding the family’s role and experience in decision making. Highly public court cases, such as the cases of Karen Quinlan and Nancy Cruzan, brought extensive public recognition to the question of the patient’s voice in medical decision making about aggressive treatment in terminal conditions. In the case of Nancy Cruzan, the US Supreme Court supported the state of Missouri’s right to require clear and convincing evidence of a patient’s wish to forego life-sustaining treatments. An outcome of that historic decision was a national wave of activity related to advance directives, including the 1991 enactment of the federal Patient Self-Determination Act, which requires that hospitals routinely inform patients about advance directives.

Although advance directives were hoped to be the method by which persons would exert their own preferences for end-of-life medical treatments, advance directives are underused and questionably effective.¹⁰ Even when properly completed before a medical event, the usefulness of advance directives often is limited by vague and nonspecific language or unavailability when needed.¹¹⁻¹³ Other problems with advance directives include a readability level exceeding levels recommended for patients.¹⁴ Also, marketplace forces in health care have confused the public about efforts to limit aggressive end-of-life care. Managed care and other “cost-efficiencies” have led many persons to fear that advance directives may lead to withholding of needed comfort care. Findings of a recent nursing study of patient attitudes about advance directives¹⁵ indicated that more patients viewed advance directives as a method of *obtaining* desired care than as a way of *avoiding* unwanted treatment.

Usefulness of advance directives appears to be especially problematic among the elderly.¹⁶ Even after 2 years of influence of the Patient Self-Determination Act, the rate in 1993 for residents of long-term care facilities, a patient group at risk for life-threatening events, was only 13%¹⁷ to 14%.¹⁸ In addition, when nursing home residents are transferred to acute care, advance directives commonly fail to accompany them.^{12,19} How to improve advance directives has been a recent focus of investigators.²⁰

Numerous studies indicate strong cultural influences on end-of-life plans and preferences; for example, African American and Hispanic patients have been found to want more aggressive life-prolonging treatment and to be less likely to plan to complete an advance directive.²¹⁻²² In other studies, advance care planning was found to pose serious conflict with

traditional values of Korean American, Mexican American, and Native American population samples.²³⁻²⁴ Clearly, autonomy is a culture-laden value, with many cultures supporting a family-centered model rather than an individual model of decision making.²⁵⁻²⁶

Without advance directives, decision making for a patient who is unable to speak for himself or herself falls to the family (or other surrogate in the absence of family). Guidelines recommend that when family members are decision makers for incapacitated dying patients, their role is to represent the patient's own values (referred to as "substituted judgment"), or for an infant or child too young to have values, the family speaks in the "best interest" of the child. However, this standard is more ideal than real. In reality, studies indicate that family members' own values, motives, or identification with the patient frequently drive such decisions.²⁷⁻³⁰ For example, in a 1994 study of Veteran's Administration patients and their surrogates,²⁹ surrogates correctly guessed patients' wishes about life supports only 60% of the time—little better than random chance.

Recent studies³¹⁻³⁶ have illuminated the family's experience of decision making. The most significant factors that affect families' decisions are their realization of futility, their understanding of whether the patient would have wanted continued aggressive treatments, and their perception of suffering of the patient. Other research³⁷ identified specific behaviors of nurses and physicians that influenced families' appraisals of their experience as positive or negative.

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However, the nursing literature has not contained extensive discussion about nursing's role in facilitating respect for patients' preferences at end-of-life. For example, although an extensive amount of medical research on the use and effectiveness of advance directives exists, little nursing research on any aspect of advance directives exists, with some important exceptions.^{14-15,38-40} Given nursing's greater degree of presence at the bedside and key role in patient communication, more research is needed in this area. Theoretic discussions in the nursing literature suggest that the nurse's role relates to patient education and other ways of facilitating patients' use of advance directives, monitoring staff's compliance to patients' preferences, verifying the accuracy of patients' preferences over time, facilitating patient-provider-family communication, leadership and collaboration in the development of systems-level policies and procedures related to advance directives, and ensuring the highest quality comfort care and nonabandonment of the patient when the treatment goal changes from life-extension to palliation and peaceful death.⁴¹⁻⁴⁶

PRINCIPLE OF BENEFICENCE: BENEFIT-HARM TEST

The principle of beneficence requires not only avoiding outright harm but also seeking the best solutions by using the "benefit-harm" test to select actions that maximize benefits and minimize harm. For terminal patients in acute care settings, the challenge is to clarify what will be beneficial, for how long, and with what margin of assurance. Surveys of acute care nurses and physicians caring for dying patients indicate they often feel compelled to act *against* their conscience by prolonging overly burdensome treatments,⁴⁷⁻⁴⁸ thus calling into question the issue of beneficence.

In the context of the principle of beneficence, several clinical practices deserve scrutiny, especially cardiopulmonary resuscitation (CPR), high-dose pain management, and physician-assisted suicide. Each practice invokes a complex ethics construct. CPR raises the concept of "futility."⁴⁹⁻⁵⁰ High-dose pain management raises the concept of "the double-effect" (ie, intended palliation vs secondary repression of respirations).⁵¹ Physician-assisted suicide pits the principle of patient autonomy against the principle of provider nonmaleficence.

CPR quickly gained acceptance as standard medical therapy after World War II, at which time success rates were very high because it had not been used in debilitated, medically fragile patient populations. In recent years, CPR as the "default" has been called into question as failing the benefit-harm test by imposing more harm than benefit. The public has been lulled, perhaps by unrealistic television portrayals, into expecting miraculous recoveries to follow heroic efforts; yet numerous studies have found in-hospital CPR success rates to be less than 20%, with very few of the patients who survive CPR recovering sufficiently to ever leave the hospital. Among the elderly, rates of success with CPR are even more dismal, varying from 0% to 5% in nursing homes,⁵²⁻⁵⁴ and with high probability of functional deterioration after CPR for those patients in hospitals.⁵⁵ When the elderly are educated about CPR and its limited effectiveness, most decline it.⁵⁶ Thus clinical ethicists now urge clinicians to educate patients about the low probability of effectiveness of CPR when patients are elderly, debilitated, or chronically ill. Some data do indicate an overall trend toward less use of CPR and other aggressive treatments. At one major medical center between 1987 and 1993, the CPR rate fell from 49% to 10% of ICU deaths, and decisions to withdraw life-sustaining treatments increased from 51% to 90% of ICU deaths.⁵⁷

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Nurses in critical care describe their roles in assisting patients and families with do not resuscitate (DNR) decisions as advocate, negotiator, mediator, educator, and communi-

cator.⁵⁸⁻⁵⁹ Although nurses in critical care would expect themselves to know their patients' preferences for DNR versus CPR, data from the SUPPORT investigation did not show that nurses were any better than physicians in knowing their seriously ill patients' preferences for CPR.⁶⁰ In interviews with 1500 nurses caring for 1763 seriously ill patients in tertiary care hospitals, only 13% of nurses reported direct discussion with patients about the patients' preferences for CPR. These discussions were more likely to have taken place under 4 conditions: (1) if the nurse thought the patient did not want CPR, (2) if the nurse had spent more time with the patient, (3) if the patient was in ICU, and (4) if the patient had metastatic cancer. In a subset of 354 patients for whom both registered nurse and physician data were available, no difference existed in the rate by which either discipline correctly identified what the patient wanted. When patients stated that they did not want CPR ($n = 127$), 53% of physicians and 45% of nurses correctly understood this; for patients who preferred CPR ($n = 227$), 79% of physicians and 83% of nurses correctly understood this. Thus the data indicate that nurses often are unaware of seriously ill patients' preferences and that they infrequently initiate discussions with the patient, perhaps because of the traditional role definition that ascribes responsibility for these discussions to physicians.

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Management of pain in terminal conditions by using high doses of opiates, regardless of the secondary effects on respiration and resulting length of life, is now widely supported.⁶¹⁻⁶³ However, barriers to effective pain management still exist,⁶⁴⁻⁶⁵ such as providers' fear of legal scrutiny or worry about patient tolerance and side effects. Current Congressional efforts to create a federal ban on physician-assisted suicide is likely to have what is being called a "chilling" effect on physician prescribing for pain.

Far more controversial than management of pain is *intended* shortening of life for mentally competent, terminally ill patients through legalization of physician-assisted suicide. Only Oregon, through its citizen-initiated legislative process, has approved legalization of physician-assisted suicide—by 51% of the popular vote in 1994 and by 60% of the popular vote in a revote in 1997. At the time of this writing, the Oregon law remains in dispute. Meanwhile, the nursing literature on the topic is expanding.⁶⁶⁻⁷⁵

PRINCIPLE OF JUSTICE: ISSUES OF COST

Efforts to put cost dollars to end-of-life care inevitably have their motives questioned. Nonetheless, the principle of justice

means that society treats citizens with a fair and decent level of health services, which implies wise use of scarce or finite resources and calls into question expensive but ineffective treatments. For example, Cher and Lenert⁷⁶ calculated the cost of providing ineffective ICU treatment to a sample of California Medicare patients who were hospitalized in 1994. Patients who died within a short period of time, which comprised 5% of the sample, used 22% of the ICU resources. Other studies suggest a similar profile. In reviewing trends in published research, Emanuel⁷⁷ concluded that end-of-life care costs 10% to 12% of the total US health care budget but costs a disproportionate 27% of the Medicare budget.

The SUPPORT study produced 2 major findings about the cost of in-hospital end-of-life care. First, when the physician and the patient were in agreement about avoiding CPR, the hospital charges for those patients differed significantly (a mean of \$21,000 vs a mean of \$35,000), which constitutes a savings of approximately \$14,000.⁹ Unfortunately, only 52% of patients who said they preferred not to have CPR actually had a DNR order written in the chart. Second, families of the terminally ill often bear heavy financial burdens. One third of the families in the SUPPORT study reported a loss of most or all of the family savings, and 29% reported the loss of the family's major source of income at the patients' death.⁷⁸ In continued analysis of the SUPPORT data, the investigators⁷⁹ found a statistically significant relationship between the family's economic hardship and the patient's preference for care that would focus on comfort rather than extending life. Although the statistical association was modest, it was large enough to underscore the great concern that economic hardship on families of the seriously ill is common, and that patients suffer worry and guilt about the effects of their illness on the family's finances.

When it is the patient's preference and when indicated, palliative care also has the added, secondary advantage of wise resource utilization. When hospice or advance directives are used, estimates of savings in the last week of life range between 25% to 40%.⁷⁷ Oregon Hospice Association data indicate that the cost of 2 days of hospital care is roughly equivalent to that of 30 days of hospice care. Medicare data for 1994 indicated that Medicare patients who were not enrolled in hospice spent 20 of their last 50 days in hospital, and Medicare patients who were enrolled in hospice spent only 8 of their last 50 days in hospital.

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ONE STATES'S PROGRESS

End-of-life care in Oregon appears to be significantly different than it is in other regions of the country,⁸⁰⁻⁸¹ at least partly as a result of an intense wave of palliative care reform that followed the Oregon physician-assisted suicide votes.⁸²⁻⁸³ For

example, although a majority of Americans die in acute care hospitals, only one third of Oregonians do so, with equal numbers of Oregonians dying in nursing homes and in home/hospice.⁸⁴ Data on 1994-95 deaths of Medicare enrollees show that only 22% of Medicare deaths in Portland, Oregon, were in an acute care hospital.⁸⁵ In addition, although nationwide the majority of elderly nursing home residents do not have DNR medical orders,¹³ the opposite is true in Oregon, where more than 90% of elderly nursing home residents have documented DNR orders.²⁰ Hospice referral is high in Oregon, with about one third of Oregonians who die annually doing so with hospice support, compared with the national figure of only 17%. In addition, Oregon leads the country in the medical use of morphine. Further, Oregon's advance directives law is comparatively liberal, permitting the refusal of any medical treatment and authorizing surrogates to make decisions for patients who are terminally ill or who have dementia and can no longer speak for themselves. The Oregon law also requires that when life-sustaining treatments are withheld or withdrawn, medication to relieve pain and suffering must be provided.

These programs and many more national and state initiatives herald a wave of reform to end-of-life care that now constitutes one of the most significant health care movements in the United States today.

Multiple factors likely have contributed to Oregon's successes in improving end-of-life care, including numerous clinical and legislative task forces, an active citizenry, a liberal governor who also happens to be a physician, and effective organizations such as Oregon Health Decisions and the Supportive Care of the Dying: A Coalition for Compassionate Care. In addition, the Center for Ethics in Health Care at Oregon Health Sciences University has played an active role in statewide conferences to improve provider practices and in convening task forces such as the Task Force to Improve the Care of Terminally Ill Oregonians, which is comprised of representatives of more than 40 organizations that serve terminally ill Oregonians.

NATIONAL INITIATIVES TO IMPROVE CARE OF THE DYING

In *Approaching Death: Improving Care at the End-of-Life*,⁷ the Institute of Medicine recently called for advances in research to improve care of the dying and for major changes in how the health care system manages dying. The need for change, both in how clinicians are prepared by their educational programs to care for the dying and in systems-level policies, is now widely recognized.⁸⁶ Numerous professional organizations have made similar calls to action. For example, American Health Decisions, a national coalition of states' citizens' groups focused on articulating citizens' values that shape health care, called for action in its report, *The Quest to Die with Dignity: An Analysis of Americans' Values, Opinions and Attitudes*

Concerning End-of-Life Care.⁸⁷ The Robert Wood Johnson Foundation (RWJ) supports several major initiatives. The foundation's *Last Acts: Care and Caring at the End-of-life* brings together professional organizations that influence clinical practice, professional training, health care financing, health care ethics, and consumer awareness. The task of the *Last Acts Coalition* is to improve communication and decision making about end-of-life care and to change the American culture and attitudes toward dying. RWJ's *Community-State Partnerships to Improve End-of-Life Care* is an \$11.25 million program that promotes broad-based changes in public policies and practices that will improve care for dying Americans.

Many nursing professional organizations are active in various national programs and initiatives. For example, the American Academy of Nursing recently announced its partnership with the American Geriatric Society, the George Washington University Center to Improve Care of the Dying, the Soros Foundation Project on Death in America, and the American Association of Retired Persons on an important joint venture—measuring the quality of care at the end of life. As another example, national nursing organizations that are concerned with curricula (American Association of Colleges of Nursing, National League for Nursing, National Council of State Boards of Nursing) recently have joined in an RWJ-funded project to strengthen nursing education to improve pain management and other end-of-life care.

The nursing research institute has been a leader in federal funding for research in this area. In 1989 the (then) National Center for Nursing Research (NCNR) sponsored a workshop on "Bioethics and Clinical Practice: Examining Research Outcomes and Methods." As an outcome of that meeting, NCNR then issued a small grants program on bioethics and clinical decision making (1991-93) to seed pilot-level research that would form the foundation for further development. This past year, nursing at the National Institutes of Health (NIH) has again led the way by spearheading a cooperative initiative in this area. In the fall of 1997, 5 NIH institutes, including the National Institute for Nursing Research (NINR) and the NIH Office of Alternative Medicine, cooperated in a research workshop about "Symptoms in Terminal Illness." An outcome of that meeting is a new program announcement at NIH called "Management of Symptoms at the End-of-Life."

These programs and many more national and state initiatives herald a wave of reform to end-of-life care that now constitutes one of the most significant health care movements in the United States today. In announcing the coalition, the honorary chairwoman of RWJ's *Last Acts Coalition*, former first lady Rosalynn Carter, said, "People's greatest fears revolve around how they will live with illness until they die. We need this coalition so that fewer people will die alone, in pain and attached to machines, and with the result that more people and their loved ones can experience dying for what it ought to be—the last act in the journey of life."⁸⁸ This reflection aptly captures the sentiment of many persons.

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