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Controversies Surrounding the Hopelessly Ill Patient

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In this article, Dr. Cassem examines the controversies which have arisen in dealing with a "terminal" or "hopelessly ill" patient. Dr. Cassem is a frequent contributor to medical journals, including Critical Care Medicine and the New England Journal of Medicine.

When does our medical treatment of dying patients become unjustified abuse? During the last 70 hours of his life in Siskiyou General Hospital, California, Emil A. Liloiva accumulated a medical bill in excess of \$10,000. His treatment included two unsuccessful cardiac operations. After his death, the County Administrator rejected the hospital's claim for the portion of the patient's bill related to those final three days.¹ This is perhaps the first of several lawsuits against hospitals arguing that certain treatment of irreversibly ill patients was unjustified.

Elliot Slater² pointed out that the two goals of medicine — the relief of suffering and the preservation of health — can become, for the dying patient, mutually contradictory. The proportion of irreversibly ill persons in whom this dilemma may exist is suggested by data from England indicating that not less than 68% of the deaths in that country occurred after a long illness, predominantly stroke and cancer.³ Not less than half of those individuals were over 75 years of age.

Reflecting the recent surge of national protest against hospitals and physicians for unnecessarily prolonging life in this category of patient, Abelson⁴ wrote, "Death of a loved one was bad enough when it was in the hands of God; now it is often a much more distressing experience." When using heroic measures to treat terminally ill patients, physicians are increasingly accused of inhumanity, experimentation, cruelty, and/or biological idolatry. *U.S. News and World Report* (May 22, 1972), *Time* (July 16, 1973), *Atlantic* (February 1974), *New York Times Magazine* (June 23, 1974), and many other popular articles, along with Patrick Henry and euthanasia societies from coast to coast, proclaim that "death with dignity" is often preferable to life without it. Celebrities have en-

dowed this movement for "death with dignity" with credibility and considerable impetus. Medical Nobel laureate Sir Macfarlane Burnet, for example, stated: "Death in the old should be accepted as something always inevitable and sometimes positively desirable. Doctors should not compel old people to die more than once." To emphasize his endorsement he carried a card with the message: "I request that, in view of my age (73), any prolonged unconsciousness, whether due to accident, heart attack or strokes, should be allowed to take its course without benefit of an intensive-care or resuscitation ward."

Indeed some blame the advancement of modern technological devices for treatment now available in hospitals for creating an "ethical crisis." On Saturday evening, January 5, 1974, ABC television network further publicized the dilemma of persons with terminal illness by showing "ABC News Close-up: The Right To Die." This program highlighted that some persons have felt it so necessary to protect themselves from excessive treatment when they are hopelessly ill that they are signing living wills. Since 1969 the Euthanasia Education Council has distributed more than a quarter million of these documents. Legislation to make them legally binding has been introduced in Delaware, Oregon, Montana, Massachusetts, Idaho, Illinois, West Virginia, and Florida. Currently the U.S. House of

Representatives is considering bill HR 2655, which would establish a Commission on Medical Technology and Dignity of Dying.

In response to similar pressures the New York Academy of Medicine on December 20, 1972, issued an official statement, "Measures Employed to Prolong Life in Terminal Illness."⁵ The statement pointed out that traditional religious ethics have always recognized there is no obligation on the part of a physician to use heroic measures to prolong life in hopelessly ill patients, and that there is no prohibition against the use of narcotics to ease pain even though such medication may shorten life. The statement urged that consideration be given to the following:

1. Mere preservation of life must not be the sole objective of treatment.
2. The physician should discuss the situation with the patient or family and should encourage both the patient and the family to express their feelings and wishes.
3. The opinions and recommendation of the family physician should be obtained even if he is not a physician of record in the particular case.
4. The views of religious advisers may be helpful.

To conclude: When, in the opinion of the attending physician, measures to prolong life which have no realistic hope of effecting significant improvement will cause further pain

and suffering to the patient and the family, we support conservative, passive medical care in place of heroic measures in the management of a patient afflicted with a terminal illness.⁵

Catholic Moral Tradition

"Euthanasia" is such an inflammatory word that its use occasionally makes rational discussion impossible. However, most of the proponents of "death with dignity" favor *negative* (or passive) euthanasia — allowing a person to die naturally from an already fatal illness. As early as 1957, Pope Pius XII stated that there was no moral obligation to use extraordinary means to prolong life in hopelessly ill patients, and added that agents such as narcotic analgesics could be administered to relieve suffering, even though their use might shorten the life of the patient.⁶ Traditional moral and medical teaching has almost universally regarded *positive* (or active) euthanasia — direct administration of a lethal agent, such as potassium chloride — as unethical and forbidden. The distinction which differentiates potassium chloride from morphine given to relieve pain includes both the intention of the physician (to relieve pain rather than to kill) and the effects of the drug. Potassium chloride, when administered in lethal dose, has no beneficial effects. Williams, in a survey of physicians six years ago, found that 89% stated they were in favor of negative euthanasia and

80% admitted to having practiced it. Only 15% favored positive euthanasia.⁷ Few physicians regard the mere existence of elaborate technological devices as a moral mandate for their use on all mortally ill patients.

In fact, St. Christopher's Hospice in London has gained international fame for offering a facility in which terminal patients can die comfortably without, in some cases, so much as an intravenous line if the latter is not warranted.⁸ Why then does the public behave as though the opportunity to die comfortably will be denied them by physicians and hospitals?

Fears of Terminal Abuse and Loss of Dignity

Medical science has in no way slowed its technological advance. Bypass grafts, intraaortic balloon pumps, membrane oxygenators, advances in transplantation and other forms of surgery, new drugs against microbial and malignant invaders, plus increasingly sensitive monitoring devices for all who survive the heroic treatments — all now offer chances of survival that approach the miraculous. Persons who would have surely died — and before might never have been treated — are now given whatever chance they have in the operating room or ICU. The condition is worse to start with and failure is common. Because the new technologies are commonly painful and usually awkward, families of the dead often question in retrospect whether the last ditch effort was worth it. Were the final heroics

only a humiliation inflicted on an individual whose demise was inevitable anyway? Couldn't he have died more comfortably, even with dignity, without them? The calculus is therefore simple: persons in increasingly desperate straits are being given better chances of survival, and the crowd who linger with this hope at the brink of death has swollen. It is a time of tremendous stress both for the sick and those who take care of them. Frustrations become accusations: doctors preserve life merely for its own sake, experiment for their gains, or commit murders of convenience; good money is being squandered on hopeless cases; healthy younger persons are excluded from ICU beds occupied by the unsalvageable; society's resources are being wasted, etc. But society continues to demand care and the chance to live, forgetting that indignity may well be an inevitable part of the gamble. More persons are taking the gamble, and, like soldiers, increasing numbers survive the conflict but have lost the war. They and their families ask, "Death is bad enough, why make it worse?"

What is "Death"?

Most persons have no desire to have their body's life maintained long after irreversible brain damage has occurred. Of course, if a person could be proved dead, then most would agree artificial support of organs is not justified. With increasing demand for transplant patient donors, pressure to define when a person is dead became intense. Because the

ethical code requires that the donor be dead before organs are to be removed before transplantation, a major contribution came with the Harvard criteria of brain death: absence of receptivity or responsivity, no spontaneous movements or breathing, no reflexes, and an isoelectric EEG, all repeated at two intervals 24 hours apart.⁹ (This definition of death is not recognized by civil law in any state except Kansas,¹⁰ Maryland, and in a special way Connecticut¹¹). Despite criticism of including EEG data among the criteria,¹²⁻¹⁴ the essence of the concept remains intact leaving the conscientious physician with a set of criteria for judging clinical death. But a paradox remains.

In Palm Springs General Hospital, Hialeah, Florida, Mrs. Carmen Martinez, 72, suffering from longstanding hemolytic anemia, asked her physician, Dr. Rolando Lopez, to spare her a splenectomy and all further cutdowns. When Dr. Lopez sought a court decision about granting her wish, Judge David Popper of Miami ruled that she had a right to refuse the treatment.¹⁵ Skillman¹⁶ argues that physicians are forced to make decisions about continuing or stopping heroic measures long before brain death occurs. Like Mrs. Martinez, increasing numbers request not to be kept alive until their brains are dead.

Why the Opposition to "Death With Dignity"?

Despite widespread general opposition to prolongation of life at any cost in an illness already ir-

reversible, the "death with dignity" movement, as well as Living Wills, have met considerable resistance. Several important factors appear to be involved.

1. *The Moral Domino Theory.* Increasing attention has been given of late to the "slippery slopes" of science.¹⁷ According to this position, the power to decide for death over life will corrupt its possessors, lead to direct (active or "mercy") killing of patients, and progress to genocide or other forms of mass extermination. The first fear received some support of the level of ethical theory for while most moral philosophers and theologians like Ramsey¹⁸ and McCormick¹⁹ sharply distinguish the positive (active) from negative (passive) euthanasia, Joseph Fletcher^{20,21} regards the two as identical. Most recently Rachels²² argues the distinction has no moral importance in that active euthanasia is more humane in many cases than passive euthanasia. Charles Curran²³ also regards the two as identical, but only after the dying process (which he does not define) has begun. Therefore, it might seem that we would be empowering some persons to do away with others (see point 4 below). Furthermore, those opposed to "opening the door" to legalization of living wills or passive euthanasia perhaps fear that it will open a slippery slope destined to end in practices little different from those of Nazi Germany — a consummation devoutly to be shunned.²⁴

2. *Difficulty Defining Irreversibility.* When is an illness irreversible? Even if we knew the probabilities of survival which are appropriate — 5%? 1%? — a different set of criteria would have to be developed for every illness or at least for each type of organ failure (e.g., heart, liver, kidneys). Imperfect knowledge in these areas causes many physicians to hesitate before discontinuing treatment efforts.

3. *Accomplice To Suicide.* Some have feared that legalization of living wills may leave those who comply with their requests open to the charge of their being accomplices to a suicide.

4. *Limitation of Care.* Dyck²⁵ has argued that the vagueness of the label "hopeless" tends to justify the limitation of care because hopeless connotes meaningless. Because the lives of irreversibly ill persons might be construed as meaningless, the care given them would be limited. For example, the old could be morally coerced to forego heroic surgery.

5. *Distrust of Human Nature.* Successful execution of living wills presupposes that those responsible for the life of the signer act in his best interest. That is, the signer would not be allowed to die just because he was cantankerous, because he arrived in the emergency ward at 2 a.m., because the hospital census was too full, etc. There are those who believe that this is too much to ask of human nature, for the same reason that it is too much to ex-

pect that every nursing home resemble St. Christopher's Hospice.

Reaction of the

American Medical Association

Perhaps the above and other reasons prompted the cautious response of medical societies in general and the AMA in particular to the question of "death with dignity." The interest of the AMA became clear when its Judicial Council sponsored the Fourth National Congress on Medical Ethics, April 26-28, 1973, although its scope was considerably broader than the "right to die." Specific treatment of the questions of active and passive euthanasia came when, at its December 1973 convention in Anaheim, California, the AMA condemned "mercy killing." Although opposing efforts to obtain a legal definition of the moment of death, they adopted the following resolution on "death with dignity":

The cessation of the employment of extraordinary means of prolonging the life of the body when there is irrefutable evidence that biological death is imminent is the decision of the patient and/or his immediate family.

Furthermore, although there has been great reluctance, for medico-legal reasons, to record orders like "DNR" (do not resuscitate) or "CMO" (comfort measures only) in the chart or order book, the American Medical Association has very recently recommended such a practice. In a recent supplement to their *Journal* entitled "Standards for Cardiopulmonary Resuscitation

(CPR) and Emergency Cardiac Care (ECC)," the following statement was made:

The purpose of cardiopulmonary resuscitation is the prevention of sudden, unexpected death. Cardiopulmonary resuscitation is not indicated in certain situations, such as in cases of terminal irreversible illness where death is not expected or where prolonged cardiac arrest dictates the futility of resuscitation efforts. Resuscitation in these circumstances may represent a positive violation of an individual's right to die with dignity. When CPR is considered to be contraindicated for hospital patients, it is appropriate to indicate this in the patient's progress notes. It also is appropriate to indicate this on the physician's order sheet for the benefit of nurses and other personnel who may be called upon to initiate or participate in cardiopulmonary resuscitation.²⁶

How Does One Decide to Forego Heroic Measures?

Even though there may be unanimous agreement that there's a time to stop trying to prolong life and evidence that 80% of physicians have at some time done so,²⁶ there are no unanimous guidelines for discharging this awesome responsibility. Two oversimplified and premature, if convenient, methods are the economic solution and the effort to define quality of life by defining who qualifies for personhood.

The economic solution is now employed in certain provinces of Canada, where each hospital is given a budget and told simply to decide how they wish the money to be spent. The utilization of facilities for the hopelessly ill

must then be weighted against their use for "more salvageable" persons. Of course the hope is that the hospital will then be forced to find the most responsible and humane solution to their life-and-death dilemmas. However, each decision to stop the fight against a lethal illness has moral, technological (or medical), legal, and psychosocial considerations as well as economic ones. To assert that the economic factors should be the sole or primary determinants of policy is surely a distortion of priorities as well as an oversimplification of a complex and grave issue. Furthermore, selection of a sole economic criterion by a wealthy nation like the United States which spends billions on methods of destroying health and lives, is open to serious question.

The "quality of life" solution seeks to help by defining the marks of human personhood so that "mere biological life" need not be prolonged. Joseph Fletcher is probably the best known proponent of this effort and includes among defining marks of "humanhood": minimal intelligence (I.Q. greater than 40), ability to communicate with others, control of existence, self-awareness, self-control, curiosity, a sense of past, present and future, creativity/changeability, distinctiveness, a balance of rationality and feeling, and neocortical functioning.²⁷ In addition to the specters awaiting us at the foot of the "slippery slope" descending from this formulation, it shares all the follies

of pure abstractions. Even though infants, our patients, our spouses, our colleagues or ourselves might not qualify as persons under these criteria, the decision to let an individual die is not necessarily clarified by their application. We would do well to heed Ingelfinger's warning: "As there are few atheists in fox holes, there tend to be few absolutists at the bedside."²⁸

Must we then say nothing ethically? McCormick²⁹ reminds us that failure to seek guidelines for these decisions leaves only the alternatives either of dogmatism or of pure concretism. There must be some line that can be drawn between vitalism (life at any cost) and pessimism (death when life becomes frustrating, burdensome, useless). Both extremes are based on an idolatry of life. McCormick used life as a relative good and the duty to preserve it a limited one. McCormick formulates life as a value to be preserved only where it contains some essential for human relationships. When, because of the condition of the individual, this potential would be completely subordinated to the mere effort for survival, then the life can be said to have achieved its potential.

Are there any practical guidelines to help determine when the time has come to halt efforts to prolong life? Collins³⁰ has employed a Dying Score derived from evaluation of five physiological parameters (cerebral function, reflexes, respiration, circulation,

cardiac action) to study irreversibility of illness in patients following resuscitation.

Two extremely important contributions toward the further study and understanding of the components of life-and-death decisions in critical care settings were recently presented in *Critical Care Medicine*. Cullen et al³¹ presented a method for quantifying the energy expenditure in caring for ICU patients, both in terms of procedures performed and in number of personnel devoted to the effort. The Therapeutic Intervention Scoring System (TISS) provides a powerful tool for quantifying the intensity of effort invested in a critically ill person. The authors do not suggest even that it be used in deciding which patients should or should not be vigorously treated. What they provide is an invaluable measure for relating intervention, cost, and use of personnel to efforts at reversing specific potentially lethal conditions. The TISS may help us answer the crucial question of what we can or cannot accomplish by medical technology in the effort to restore health.

Tagge et al³² presented what appears to be the most promising method yet for deciding responsibly when specific interventions are no longer reasonable. This Mount Sinai classification of patient care categories avoids entirely the pitfalls of apriori criteria which must be met in order for a decision to be made to decrease the intensity of care

given to a critically-ill person. Its genius lies in its establishment of a process, openly acknowledged and regularly exercised, by which the entire treatment (ICU) team is forced to confront the question of what is best for the whole person in question. As such, the real question initially introduced — is our intervention, in fact, abuse disguised as treatment—is forced from the shadows of taboo and secrecy and confronted in a way that guarantees (even forces) open, maximal communication. It seems clear from the experience at our own hospital that almost all the disputes over whether a terminally-ill patient should be treated more or less intensively have arisen because communication was faulty. One, of course, could argue that the team as a whole could be corrupted by possession of such arbitrary power. However, when the family and the patient (whenever conscious) are partners to the decision, the threat of the “slippery slope” is far less likely.

The Hardest Work

Talk of a degnified death may be, in fact, a form of self delusion. Suffering, painful separation, grief and anguish are seldom entirely absent from any death regardless of our efforts to wish it away by slogans.^{33,34} There may be an illusion in the minds of some that once the decision is made and no further heroics will be used, all difficulties are solved. That point is precisely where they are most likely to begin and where most care and attention need be

given to both patient and family. The responsibility for making decisions to continue or omit extreme measures is awesome enough. After they have been made, the delicate and sensitive issues of human suffering and loss demand even more compassion and courage to continue care under those circumstances. Young physicians and nurses need more guidance in discharging these responsibilities. What our colleagues have confronted alone in past centuries we must now face together.

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1975 ANNUAL MEETING

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