

D OCTORS, MERCY, & THE TAKING OF LIFE

by Carlos F. Gomez, M.D., Ph.D.

Death, Josef Stalin once said, solves everything.* It ends messiness and ambiguity, indecision and doubt, suffering and pain—along with all the heroic and ennobling aspects of life that give rise to human flourishing.

Death, and our approach to it, has occupied a large part of public debate these past few years. In part, at least, this is because of a group of enthusiasts in this country who have suggested that a planned death—an intended death—may be a better alternative for some than the uncertain and often painful exit that many of us endure. The euthanasia movement, here and abroad, has fired the imaginations of many, using a seductive rhetoric portraying physician-assisted suicide as a humane and peaceful way of leaving this life.

The Euthanasia Debate

As a physician who works primarily with indigent and underserved patients, and as an opponent of physician-assisted suicide, I have watched, with growing dismay, the evolution of a movement that threatens the civil rights and well-being of our most vulnerable patients. I worry

that what was once considered, at best, a fringe element in the field of medical ethics, has gained new respectability, so much so that what was once profane and taboo—the intentional killing of an innocent human being—has become almost pedestrian. Conferences, movies, and even a best-selling book have all given credence and popularity to the idea of physicians as co-agents in suicide.

* I am indebted to Sidney Callahan for this quotation.

Co-opting Language and Blurring Boundaries

How have we come to this state of affairs? How have we reached a point where a good number of citizens will seriously countenance allowing physicians

to help their patients kill themselves? At least part of the answer lies, I think, in a corruption of language, in the success with which the euthanasia movement has co-opted the words and phrases of earlier discussions

about dying with dignity. This intentional muddling of language has blurred the enormously important distinction between not intervening medically to forestall a terminally ill patient's inevitable death, and killing the patient outright.

Many of us in the medical community wholly oppose the intentional killing of patients by their physicians (or by anyone else, for that matter), yet believe there are times when it is not only appropriate, but imperative, to obey a patient's request for withdrawal of life-sustaining treatment. Part of this sentiment grows out of a consensus that has emerged over the past twenty years, which suggests that the availability of medical technology is not the same as the appropriate use of technology.

The quest for "death with dignity" (for lack of a better phrase) was born, in part, out of a reaction against an obsessive, unwelcome, and unfruitful use of medical technology on patients who had either expressed a clear preference against the use of such technology (such as mechanical ventilators), or whose chance of recovery was so minimal that life-sustaining treatment became but an exercise in temporizing against an inevitable and imminent death. Thus, at one superficial level, people became distrustful of a medical system that seemed to be slavishly inflicting its technical wizardry on unwilling or unsuspecting patients.

Not every person's death needs to be punctuated by the fits and starts of medical intervention; sometimes, perhaps often, it is more appropriate simply to allow one to die, powered solely by the body's own dwindling reserves, while making sure that ordinary human care and concern is provided.

This reaction against overly intrusive medical treatment also

Don't Hasten Death

by Anita Marie Fusco

My brother Michael, 15, died quietly in January 1976 after a painful nine-month battle with leukemia. Chemotherapy had taken his hair. His skin was bruised, his arms full of intravenous needle holes.

Still, my mother says, his death was strangely beautiful: A peaceful look came over his face; my parents knew his pain was over.

After hearing so much about Derek Humphry's suicide how-to book, *Final Exit*, I asked my mother if Michael ever wanted a doctor to speed his dying.

"No," she said. Michael suffered—but "wanted to live until the very end."

I understand. Not long ago, I too lay in a hospital bed, thin, bald and bruised, chemicals dripping into my veins. Like Michael, I had leukemia. Unlike him, I am alive and healthy today and rejecting the notion that doctors should be able to accommodate seriously ill patients who wish to die.

Having cancer wasn't fun. At times it was sheer agony. But family and friends held my hands while I was wracked with nausea, lifted me when I was too weak to stand and buoyed my spirits with love and concern.

Was my quality of life diminished? Physically, yes. Emotionally, no way. I don't know that I've ever felt more loved. And at my weakest and most vulnerable, that love let me hold on to my dignity.

That's also why I know that what Mr. Humphry offers is no "exit" at all. Rather, it's an escape—one that sells short the human spirit.

Mr. Humphry needs only to see the patients I've seen, laughing and finding joy in life until the day they die, to know there is such a thing as triumph of the spirit.

Most terminally ill people don't want the easy way out. They cling to life, savor it; their eyes have been opened to its richness. They cherish their time on this earth.

A suicide manual won't ease the understandable fear of death. That takes compassion from families and care-givers, who can help make dying truly "the final stage of growth."

But Mr. Humphry's approach disturbs me most because it removes hope from the dying process.

When all hope for a cure is gone, another hope emerges, that in dying, we may find and hold to the very roots of life: love, laughter, compassion, joy and forgiveness.

Why would anyone advocate ending life before those important discoveries can be made—and enjoyed?

Let's not tell people how to hasten the inevitable. Rather, let's teach them how to reap the blessings—and they are many—of preparing to die.

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bespoke a deeper understanding of the unchanging verities of human existence: an appreciation of our ultimate frailty, of our mortality, of our powerlessness, finally, against the inevitability of bodily death. It was, despite some excessive rhetoric, a welcome reordering of an overbearing and arrogant medical model, which had come to see all of human disease as conquerable, and death as an enemy always to be engaged and vanquished.

But it is important to note that more than two decades of debates over life-sustaining treatments have, until rather recently, stopped short of endorsing physician-assisted suicide. In fact, many early legal and non-legal commentaries were at pains to point out that termination of life-sustaining treatment was distinct from euthanasia. The first was an act preserving the autonomy and dignity of the patient; it was a return to a sturdier ethic that put patient care and comfort at the center of concern. The latter was an act of homicide, no matter how well-intentioned or how well-disguised.

Without the rest of us quite noticing, however, the euthanasia movement has appropriated these same arguments (and tapped into the same vein of distrust of the medical profession) to further a quite different end. Patient autonomy now becomes a license for engaging a public institution, the medical profession, in what is at best a tragic and essentially private act: suicide. What was initially a request to be left alone, to be allowed a peaceful death now becomes a demand: that death be directly administered.

Moreover, patient dignity undergoes a similarly bizarre metamorphosis, so that to enable a dignified death sometimes means that one kills, or that one enables the self-killing of the agent whose death we wish to

dignify. Ironically, those who were once at risk of languishing in an interminable medical twilight now face the possibility of another unwelcome and untimely end, again at the hands of physicians.

Consent Cures All Evil

This trend derives from a paradigm that is fundamentally flawed. According to this model, the core of the doctor-patient relationship is a contract, much like any other in society. The physician and patient are essentially strangers who exchange goods and services: one offers medical knowledge and skill; the other offers money. Thus the encounter between a patient and physician begins to look very much like a transaction. Indeed, the rise of so-called "medical consumerism" and the profession's willingness to accommodate and even encourage this approach to medical care transform a patient into a client.

While many view this as a positive development in the evolution of the doctor-patient relationship, it is, at best, a mixed blessing. To suggest that what transpires between a physician and his or her patient can be captured and described by the same model that describes the selling of a used car, for example, misses the point of doctoring altogether. It ignores the fact that professionals profess—that is, declare publicly—something about the nature of their vocation that distinguishes their public activity from pure marketeering. The nature of the profession, the public declaration that one makes, is that one serves ends outside of oneself; that the object and aim of one's powers and skills is the restoration or preservation of the patient's health.

The profession further defines itself by limiting its sphere of activity, what ethicist Albert

Jonsen has called "the physician's frame of reference." This means that there are some possibilities, unique to medicine, which the well-professing physician does not pursue. For example, it would be beyond the physician's frame of reference to prescribe an ineffective drug, such as laetrile, for a newly diagnosed patient with cancer, irrespective of how much or how sincerely the patient demanded it.

Take note that the patient is assumed competent to make such a request and is not coerced into making it. In other words, the patient meets what is now the almost absurdly minimalist criterion for the contractual paradigm: a consenting, competent adult who engages the willing physician for services which only the physician can render. Yet, irrespective of the patient's volition—and despite a particular physician's willingness to provide such a service—to acquiesce to such demands betrays the profession and the end which it serves, namely, the patient's health. Consent, by itself, does not grant sufficient license to engage in non-professional activities. Consent possesses no magic and cannot change the basic nature of an activity. It cannot, by itself, make right what is fundamentally wrong.

This is a point not to be trivialized, for the euthanasia movement's central argument hinges precisely on ignoring the distinction. If doctoring is just like any other activity, and if the activity's legitimacy rests not on an ethic *intrinsic* to the profession, but on the acquiescence of the parties involved, then indeed, a competent adult can rightfully request assistance with suicide (or with many other activities).

In other words, if the act is morally neutral—and this is, at a minimum, what the euthanasia movement suggests—then the

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desire to be killed outweighs the prohibitions against euthanasia that have, until now, kept the medical profession from participating in patients' suicides. If physicians are, finally, tradespeople meeting a consumer demand (and make no mistake, there is, at least on the surface, a demand for such services), then the only brakes on such activity would be physicians' willingness to provide the service, the patients' demands, and whatever regulatory oversight society chooses to monitor assisted suicide.

Uses, Abuses, and Slippery Slopes

As bizarre as that scenario sounds, that is precisely the point at which we now find ourselves. We have, to a greater or lesser degree, accepted as a society at least the *possibility* that euthanasia might be a good thing under some circumstances. What is left for us to decide, it is said, is how best to regulate the practice. Thus the bulk of proposed legislation to decriminalize physician participation in euthanasia deals with procedural matters: what constitutes a competent request, who may honor such a request, how does one document it, and so on.

The "Humane and Dignified Death Act," the first of recent legislative attempt to legalize physician-assisted suicide, failed to garner sufficient signatures to be placed on the 1988 ballot in California partly because opponents of the measure pointed out (appropriately) that there were insufficient safeguards for the practice. Among the many dangers of euthanasia lies the possibility that this practice which exalts patient self-determination would become, in the end, the enemy of autonomy: One cannot exercise choice if killed without one's consent.

Proponents of legislation to decriminalize euthanasia have insisted, however, that such dangers can be circumvented if enough attention is given to regulatory safeguards. And thus, each successive attempt at decriminalization—Initiative 119 in Washington state and a new euthanasia initiative in California—aim at crafting laws that will, so its sponsors say, reserve the practice only for extreme cases where consent can be clearly documented, so that the practice will be immune from abuse. The dangers of unbridled medical killing can be avoided, so the argument goes, if we write legislation with enough clarity and regulatory force.

My own study leads me to conclude that such precision is not obtainable and, in the final analysis, not truly wanted. My research on euthanasia in the Netherlands—where the practice is tolerated, yet formally forbidden—suggests that even under the best of circumstances the practice begins to degenerate quickly into something altogether different. In four out of 26 actual clinical cases of euthanasia that I studied in the Netherlands, it was clear that the patients were incapable of consenting to their deaths.

In one case, a two-day-old child with Down's syndrome and duodenal atresia was killed by the physician, with the tacit consent of the parents. In another, the patient had a massive stroke and was incapable of giving consent; the physician elected to euthanize the patient anyway because, to paraphrase the doctor, the patient would surely not have wanted to live this way.

The euthanasia movement in this country has always pointed to the Netherlands as the paradigm for "humane euthanasia." So, when I initially presented my findings, I was met with skepticism. I was, after all, only one observer on the scene, and the numbers I reported were relatively small. In recent months, however, the Dutch themselves have admitted to results quite similar to my own. In fact, the Dutch findings are a good deal more worrisome.

The Rimmelink Report, a large study carried out under the auspices of the attorney general's office, reviews the practice of euthanasia in Holland and clearly documents instances of involuntary euthanasia. A remarkably sympathetic synopsis of the report in the September 14, 1991, issue of *The Lancet* admits that a small percentage of cases of euthanasia were involuntary. It goes on, in a memorable phrase, to justify this apparently small number of homicides (for this is the appropriate terminology here) by noting almost blithely that "most patients were not coerced" into their decisions.

However, this synopsis completely, and conveniently, leaves out approximately 1,000 other cases of involuntary euthanasia. These were deleted from the findings published in *The Lancet* because they did not meet the Commission's criteria for "model decisions concerning the end of life." Some of these patients were

given intentionally large (and, not surprisingly, lethal) amounts of narcotics in order to hasten their deaths. They did not meet the criteria of euthanasia because there was no public declaration of intent to kill. This ruse, however, does not change the outcome: the patient is no less dead and the physician no less morally culpable (though it may, in these bizarre times, make the physician immune from prosecution).

Not surprisingly, the euthanasia movement in this country has been loathe to criticize the Dutch report. Nor does there appear to be much consternation on the part of the Dutch government over a report they commissioned which clearly shows that medical killing has taken a form that, even under the most liberal of interpretations, falls outside of what is countenanced, at least officially.

The Dutch paradigm is illustrative on a number of counts, but the strongest is its evidence that this practice is corrupting. Once we accept intentional killing in medicine, once we give license even under the strictest of criteria to physician-assisted suicide, the nature of the medical profession changes fundamentally.

My critics on this subject have suggested time and again that I am employing an intellectually disreputable argument, the slippery slope. But I postulate no slippery slope; I am merely describing the times in which we live. The current situation is less like a slippery slope and more like a precipice, on which we are poised at the edge staring into an abyss.

If history is any guide (and it usually is), the first to be nudged over the edge, however gently, will be those least able to protest: the weak, the demented, the stigmatized, the marginalized. Those who live at society's fringes have always been at risk from abuse and injustice. They are deemed by society to be entirely dispensable. They are, however, the ones about whom we should be most concerned and the ones whom this ill-conceived practice of euthanasia would probably affect most severely.

Those of us who oppose the goals of the euthanasia movement should admit, up front, that there are deaths which are messy and painful. We should also add that taking care of dying patients is more difficult and expensive than killing them outright and

that the task of taking care of dying patients has been woefully understaffed and underappreciated for many years. But we should not let the voices of death beguile us, nor should we be demoralized by their growing popularity.

We should clearly and honestly admit the failings of our medical system, even as we take note of remarkable recent advances in pain control and terminal care. We should also be a source of encouragement, not only for the dying, but for the remarkable people who spend their days and nights caring for them.

We should, finally, agree that a bodily death does, in its own good time, solve everything, but that killing solves nothing. And we should be clear-headed about the difference.

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