Human Dying Has Changed

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The act of dying has changed in response to social changes accompanying scientific and technologic progress. Increasingly, at least in the Western world, people are dying within strange medical establishments without the support of their loved ones and without an opportunity to take part in decisions relating to their own deaths. This article deals with the serious personal and social distress arising from this state of affairs and describes the emerging role of bioethics as a discipline seeking to develop options that are more humane.

Man’s passage from life on earth has a dual dimension: the existential process of dying and the transcendent, mysterious dimension of the beyond. This article examines the first dimension, the existential process of man’s death, without forgetting the unfathomable mystery of spiritual transcendence. More specifically, it describes the characteristics of the new form of human dying as an effect of modern science, technology, and life; examines the serious problem created for the patient by the change in the form of dying; and attempts to describe the solution to this problem that has begun to emerge around the world in recent decades.

THE ALTERED FORM OF DYING

Let us start with an easily verifiable fact: Modern medical science and technology, the philosophers of the last century, the writers of the present century, our communication and entertainment media, and the consumer society of the present century have changed the dying process from what was traditional in almost all countries, at least in the Western world. It is not necessary to point out the specific scientific and technologic factors involved to observe that “... health care in hospitals, with their highly developed technology, has changed the form of dying” (1).

In past times, most people died at home, knowing they were going to die, surrounded by their loved ones, with religious care, and in possession of all the facilities required for making both minor and major decisions with regard to their situation. At present, to the contrary, “... statistics from the United States of America reveal that more than 80% of natural deaths take place in clinics and hospitals where the means for prolonging life are increasing every day and are provided to practically all patients. Very frequently these patients end their days in isolation and solitude with tubes inserted into all their orifices and with needles in their veins, waiting to breathe their last breath” (2).

Death is becoming “hospitalized”; that is, it is being taken out of homes and social life and being hidden in clinics and hospitals. Anesthesia, drugs, and tran-
quilizers diminish the patient’s consciousness, and with it the patient’s freedom.

Frequently, the truth is kept from patients with regard to the seriousness of their situation. "Somehow," a physician notes, "many of us have come to believe that we have a right to lie to patients under the assumption that we are protecting them from the cruelties and realities of life and death. This is the first step in the destruction of an honest relationship with the patient" (3).

Recently, in the United States at least, the pendulum has been swinging back. In the 1960s the practice of nearly all U.S. physicians was to hide the truth from their patients. In the 1980s, however, more than 80% apparently believed in telling them the entire truth. Nevertheless, this change has not taken place in other countries of the Americas, most notably those of Latin America, where patients and their families tend to leave nearly all the initiative regarding information and treatment up to the physician.

Together with these data of scientific origin regarding death, it would be well to provide some social information. Not many years ago, N. Versluis (1) presented a good analysis on this subject in which he made the following observations:

Our times fail to recognize death in the full measure of its gravity. There is no place in modern life for thinking of death. It is feared, and perhaps because of this, contemporary man prefers ignoring it and playing with it (which is another form of avoiding it) rather than facing it by attempting to understand it and accept it as part of real existence. We are so familiar with death through the communications media that we have made ourselves insensitive to the possibility of dying and prefer to consider it as something alien to us. Motion pictures, television, novels, and soap operas are abusing the phenomenon of death, which they circulate as an easily acquired commodity for consumption. The public demands it in great quantities, accompanied by violence, which it accepts and even enjoys with lamentable debasement.

The American sociologist G. Gorer has a name for this phenomenon of the consumer society, the manipulation and enjoyment of violent death. He calls it "the pornography of death" (4).

What a strange contradiction the twentieth century manifests with regard to death. On the one hand it wishes to ignore real death, and at the same time it abuses death’s image in the form of play and violence through the communications and entertainment media. The increasingly common attempt in various countries of the world to conceal death as much as possible by making up corpses in order to give viewers a lifelike impression may be considered symbolic of the social concealment of death. On the other hand, children are taught "to kill" in play, and adults are sold the article of death in motion pictures and television programs.

Another important change in the form of dying involves prolongation of human existence on two levels: First, most people today die in middle or advanced age; and second, the act of dying itself has been prolonged.

In most countries life expectancy at birth has practically doubled. In past centuries, as a result of wars and plagues, life expectancy at birth was roughly 30 years for men and 35 for women (5). Today, life expectancy in the developed countries is more than 70 years. It is true that middle age has been extended, but it is also true that the infirmities of old age have increased and become generalized. The number of elderly people is increasing disproportionately around the world,
accompanied by the well-known problems of this stage of life and even some new ones.

Science and technology are also contributing to prolonging the process of dying. The scientific and technical progress achieved in the health sciences in this century are of such magnitude that one might say with pardonable exaggeration that physicians are no longer allowing death to happen. If in past centuries a cancer of the pancreas or myocardial infarction typically left the afflicted with little time to live, those who suffer them today may survive for months or even years enduring a slow death; there are even those who make full recoveries and return to normal life.

If, in addition to this prolongation of life, it is considered that many physicians say little if anything to their patients regarding their true situation, and at most provide only family members with information about the patient's status, it can be seen that more and more frequently the patient is no longer master of his own death, since he does not know when he is going to die, nor can he make appropriate decisions based on pertinent information.

In summarizing the new form of dying in the twentieth century, it can be said that death has been largely postponed until old age, since life expectancy in many countries is now more than 70 years. Furthermore, the act of dying has been prolonged, since it may go on for months and even years; it has become "scientific," since nowadays people die in hospitals, surrounded by health personnel and ministered to by technical equipment that tries the dying person's patience; it has become passive, since in many places physicians, in agreement with family members, make decisions regarding hospitalization, surgery, operations, and the like without even consult-

ing the patient; it has become profane, since religious services in accordance with the beliefs of the patient are tending to diminish and even to disappear in some health centers; and it has become isolated, since the patient dies alone and abandoned, even while surrounded by the most varied and attentive health personnel.

Real death has thus been "hospitalized," in contrast to the social image of death disseminated and manipulated by the communications media; and so real death is often deprived of its significance and transcendent relationship to the beyond. It has become superficial and trivial.

THE PROBLEM WITH THE NEW FORM OF DYING

Clearly, all this creates a serious and delicate problem for the patient. Therefore, rather than enumerating a series of problems, as if each were independent one from the other, it appears more worthwhile to bring the difficulties involved together and consider them as one central problem for the purpose of exploring their ramifications and consequences.

The one fact which appears to underlie almost all the characteristics of modern dying just described is precisely that science, technology, and society have wrested death from the patient, since he now behaves in a passive manner with regard to the dying process.

In general, physicians and health personnel devote themselves to treating the patient with all kinds of technologic advances, guided by the supreme criterion of prolonging his life, if only his purely biological life. The hospital, and to some extent family members, take charge of the death of the patient, who is no longer allowed to die his own death. He suffers
it but is not master of it, for they have taken it away from him. This may be done with his complicity. His desire to live forces him to deliver himself into the hands of health professionals, who from the surgeon to the stretcher carrier are in charge of all matters, great and small, regarding the patient and his physical and personal surroundings.

In this way hospital centers have taken over the patient's process of dying. They advance or delay the moment of his death. They send him to an intensive care unit or to the operating room when they wish, and also remove him at will, usually in accordance with the demands of science and technology.

This is perhaps what most characterizes present-day dying. People die "scientifically" in hospitals and clinics, surrounded by strange men and women dressed in white and supplied with all kinds of apparatuses. They are removed from their families and religious settings and interned in a white jungle where physicians are in charge and science and technology prevail—all this with a view to distancing death and prolonging life to the utmost extent that the scientific and technologic capabilities of the institution will allow.

The key people making decisions here are not the patients but rather their closest family members and the health professionals involved. We use the plural here advisedly, since it is more in keeping with the fact that relatives are typically numerous and health professionals legion.

It is worth repeating that the inevitable result of this kind of medical treatment, which is becoming known as "aggressive" or "invasive" medicine, is to take death away from the patient. The individual does not make either major or minor decisions, largely because he is ignorant of the diagnosis of his illness and of its prognosis. Treatments are concealed from him, and neither his collaboration nor his active opinion with regard to his illness is requested of him. He is isolated as a precautionary measure, and visits from family members and friends are restricted. Such isolation is accentuated to a maximum degree when he is transferred to an intensive care unit.

This process of physical internment and isolation can be regarded as "deprivation of death." From the traditional act of dying at home, surrounded by loved ones and provided with religious support, a solitary death has been created in which there is an increasingly limited encounter between a blurred and poorly informed consciousness on the one hand, and an increasingly silenced and silent transcendence (God) on the other. If this circumstance is combined with reduction and practical absence of the patient's freedom, it is neither unreasonable nor exaggerated to say that science and technology have deprived the patient of his death.

What problem is created for the patient by this cutting off of the personality, this isolation from others, this passivity, this ending of existence without consciousness of the end or the beyond? To begin with, the absence of the self and lack of consciousness and freedom signify a regrettable diminution of the patient's personality. Man is truly measured by his personal dimension, not by his physical size, weight, or build; neither is he measured by his biological life or the number of years it endures, without due regard for its quality or the participation of the individual in healing processes.

Illness and, above all, the dying process place man, even if he does not believe in God, before the most important decisions of his life; and what the healthy man does not understand if he has never suffered severe illness, is that as the body
becomes ill, the lucidity of the personal self is not spared. The mind, the spirit, and the total man also fall ill, and in this circumstance he must confront the meaning of his last days.

Today, more than ever before, the physician needs initiation in a sound anthropology that will teach him to approach each patient and treat him as the human being he is, one whose interior world is being put to the test, whose anxieties and fears cannot be ignored; a human being with his own transcendence and his own overture to God. To deprive the patient of his mental lucidity and the degree of consciousness required to dispose of his goods, to keep him from saying goodbye to his loved ones, speaking to his lawyer and to the chaplain about his problems of conscience and his desire to put himself at peace with God and mankind, is to create a problem for him, the problem of having to make decisions with regard to God and his fellow creatures and not being able to do so for lack of information and freedom.

This is precisely what is known as dying an undignified death, dying like a plant or animal.

We must defend the rights of the patient, and we must find again the most essentially human way of dying—that of dying in full awareness and in freedom.

Modern-day medicine, which deserves great praise and gratitude for its enormous conquests, must recover the human values of the physician and the patient as a means of making health professionals see the need to restore the patient’s awareness and freedom, together with his right to assume his place regarding God precisely at the moment when he is terminating his earthly life.

The patient tends to benefit from such a cooperative attitude, since treatment typically promotes a cure when it replaces a passive attitude with active participation (6).

The need to recover death is great. What can be done, then, to retrieve it?

TOWARD POSSIBLE SOLUTIONS

Let us attempt to generalize about what has been done in recent decades throughout most of the world, since the new form of dying has been appearing everywhere, and everywhere has been evoking a similar response.

The response has been somewhat delayed. The modern world has become insensitive to traditional moral values, and perhaps for this reason the effects of the involuntary dehumanization of medicine were not immediately felt, either in the area of research or in that of treatment provided at hospitals and clinics.

However, the response, when it came, assumed a name: bioethics. From it and with it we are going to see the world’s response in favor of maintaining contact not only with the fact of death but also with the health of human life in general, with research into human life from conception until death, and with the applications of research. Bioethics is not a discipline that is cold, calculating, abstract, defined, and precise in its methods and content. It is rather a movement, an interdisciplinary effort, a growing process of searching out moral values; and as such it must be given time to assume form, meaning, method, and organization. It is not an already-existing standard brought in from the outside with mandatory legal power over the medical world or hospital personnel—as if it were intended to punish a criminal, reprimand him, or deprive him of his life or liberty.

Let us make this point very clear: The health professional is above all a benefactor of mankind. What he is doing for humanity cannot yet be evaluated to its full extent and depth. As the physician since ancient times has been compared to the priest, and has recently been practically
transformed into the lord and master of life and death, it is not surprising that he is ironically compared to God himself. Physicians are "playing God," the magazine Newsweek noted a few years ago on its cover and in a feature article (7).

Let us not forget the historical-social premise stating that science provides power (8) and technology provides progress and change. Rather than committing a sin, the modern-day physician is making a discernible and regrettable error; he believes in good faith that science and technology have made him the master of human birth and death.

Such, however, is not the case. God must continue to be God; and man, whether a technician or a scholar, must be aware of his limitations and become a tool in the hands of God for the good of humanity.

Let us return to the universal response in favor of the patient's recovery of death and mastery over his dying. Let us recall some of the events that have given rise to this international response in favor of the humanization of medicine and defense of patient rights that is called bioethics.

The greatest violations of human freedom that have taken place in this century—especially those systematically perpetrated more by dictators than by physicians, violations that have regrettably employed the practices of aggressive medicine, in places such as concentration camps and in human experiments carried out on prisoners—have induced the highest authorities to defend the right of all human beings to informed consent prior to any experimentation, hospitalization, or medical treatment.

Nuremberg, Helsinki, Rome, the United Nations, the World Health Organization, the Pan American Health Organization, Geneva, and the Holy See (9) are names that will long be associated with human welfare. They are the names of sites or of international organizations linked to pronouncements made at the highest level in defense of human freedom, especially of those suffering from conditions found in prisons and concentration camps and those with physical or mental disability.

To cite another example, the World Medical Association, meeting in Lisbon in 1981, approved a Declaration on the Rights of the Patient, which, inter alia, provides that after having been properly informed of the treatment proposed, the patient has the right to accept or reject it and to die a dignified death.

The intervention of governments through their legislative and judicial organs has played an important role in emphasizing the ethical nature of medical acts, and the communications media have seen fit to publicize such interventions nationally and internationally. This has had a great influence on the emergence of bioethics, particularly in the United States (10).

As the popular saying goes, "for great ills great remedies." Such a broad and offensive abuse of human freedom required a commensurate solution. It was this state of affairs that gave rise to the world response in support of twentieth century man.

It is patently evident that the highly developed research of this century has placed more emphasis on science than on ethics. And, on the whole, the situation in which modern medicine and hospital technologies have placed the patient is one where his freedom is restricted and even abused, since he usually dies without realizing what is happening.

Given these circumstances, it is not surprising that a response favoring patients' rights has emerged and that the influence of the Foundation for the Right to Die with Dignity is spreading throughout the world. This worldwide movement has set itself the goal of helping all human beings become aware of their
right to die as people and recover and exercise their right to make the most important decisions with regard to the process of dying.

THE BIRTH AND NATURE OF BIOETHICS

The worldwide response of international organizations; local governments; legislative, judiciary, scientific, and religious authorities; and individual researchers and scientists was given the name of "bioethics" less than 20 years ago by a United States oncologist (II). This author sought to create a new field of study and a movement among scientists around the world, and to initiate interdisciplinary research that would serve as a bridge between ethics and the biomedical sciences.

What are the goals of this new discipline? Bioethics seeks to link ethics with biomedicine, to humanize medicine, and among other things to help all patients (and we will all be patients someday) become aware of the right that will help them to die with dignity.

Bioethics is characterized by the following features:

- It has evolved in a scientific setting as a need perceived by health professionals themselves in the broadest sense to protect human life and the environment.
- It arises from an interdisciplinary effort by many health professionals. It is a search of various fields of biomedical and professional knowledge in which sociologists, psychologists, ethicists, philosophers, and theologians, among others, are participating, joining together to explore the human values that inspire their work.
- It is not a ready-made science with "prefabricated" ethical formulas. As many biomedical problems are new ones, it is not surprising that a need has arisen to seek new perspectives capable of guiding investigative work in this area. So although bioethics' point of departure is traditional principles and values, it seeks to use these to find new solutions to the new problems posed by biology, genetics, and many other sciences.
  - It is founded more on reason and the good moral judgment of its practitioners than on any school of philosophy or religious authority. Consequently, its principles and orientation are of an autonomous and universal nature.
  - It does not seek so much to involve itself with elaborate theories as with practice, so as to provide ethical guidance for researchers, technicians, scientists, lawmakers, and political leaders that will help them correctly assess the human repercussions of their work and will enable them to respond with appropriate measures.
  - It especially seeks to humanize the environment in clinics and hospitals, and to promote the patient's rights to exercise a healthy liberty and to end his days with a dignified death.
  - It does not seek to regulate medical practice with regard to the doctor-patient relationship (which remains a concern of medical ethics). Rather, it seeks to make all biomedical professionals aware of the international codes on human experimentation and of legal requirements with regard to health practices in their respective countries.
  - It seeks to integrate ethics with the biomedical sciences for the purpose of persuading health professionals
everywhere of the need to take account of the patient’s humanity and to include the ethical dimension of health problems in all medical decisions.

- Because bioethics is not yet a clearly defined field, it is not surprising that a certain vagueness and imprecision blur its concepts, scope, and operating methods.
- The presence of bioethics is most evident at bioethical centers and institutes where interdisciplinary teams are engaged full-time in exploring, teaching, and disseminating moral values capable of serving as a basis for biomedical research. Its influence is also clearly felt at national and international conferences, on committees and commissions, in libraries and specialized journals, and in all kinds of publications.
- Bioethics is more concerned with seeking the ethical dimensions of new problems created by the biomedical sciences than it is with traditional treatment of medical subjects. This is evident from the content of any publication that deals with bioethics. When it studies traditional themes—for example, abortion or euthanasia—it does so in its own way with new perspectives.
- While bioethics is being taught to future physicians at medical schools, its principal aims at present are outside the classroom. That is, it seeks to make itself a presence in scientific research circles and hospitals in order to offer humanizing and moral values and to see patients’ rights prevail.

REFERENCES


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