

The Linacre Quarterly

Volume 56 | Number 1

Article 9

February 1989

The Health Care Professional and the Care of the Dying: The Crisis of AIDS

Peter J. Riga

Follow this and additional works at: <https://epublications.marquette.edu/lnq>

Recommended Citation

Riga, Peter J. (1989) "The Health Care Professional and the Care of the Dying: The Crisis of AIDS," *The Linacre Quarterly*: Vol. 56 : No. 1 , Article 9.

Available at: <https://epublications.marquette.edu/lnq/vol56/iss1/9>

The Health Care Professional and the Care of the Dying: The Crisis of AIDS

Peter J. Riga

The author is a Houston, Texas attorney who received his licentiate in philosophy and his master's degree from the University of Louvain, Belgium. He holds a doctorate in philosophy from the Graduate Theological Union, Berkeley and a doctor of jurisprudence degree from the University of San Francisco Law School.

The image which our society has of nurses, doctors and other medical personnel is intriguing. It is an image evolving over the last century in the same way medicine has evolved. And like medicine, this image is undergoing dramatic change.

Before World War II, the image of medical personnel was that of a Florence Nightingale, absolutely devoted, but with little technical and medical expertise. The devotion of these people equaled their powerlessness, since medicine failed as often as it succeeded. On the whole, failure or not, medicine was accepted as part of a larger human destiny which was inevitable. There was not yet the great fear of death and its denial. Death was part of each person's life.¹ Medicine recognized its limitation in the natural scene of things. The war on disease and death had not yet been declared.

After 1945, the era of great hope in medicine arrived: vaccinations, antibiotics, penicillin, organ transplants, genetic mutations, fetal interventions, by-pass operations, pharmaceutical miracles, hi-tech machines and computers, etc. Advances were made everywhere. Medicine was no longer a hit and miss affair or an art or an inspiration, but a veritable savior which could do almost anything it set out to do. Medicine was no longer the instrument of destiny, but destiny itself. Man created its own destiny.² People expected medicine to succeed, which it often did. Hopes and possibilities seemed to be infinite as the average human life span increased to 75 years. The health care professionals became the new

high priests who were almost worshipped. When they were recognized to be only human by AIDS, resource limits and malpractice attorneys, man's view of doctors changed.³

But to demand miracles of doctors and medical personnel was foolish from the beginning, because medicine could never deliver salvation. People still had to die whether at five or 85. The AIDS epidemic brought this home like a vengeance. There was the downside of medicine as well: medical personnel became cold technicians who seemingly were indifferent to their patients. As we shall see, this indifference masked a whole series of motives. While becoming more and more demanding, the public also became more and more critical of doctors who at once fascinated them, but whom they found to be less than human.⁴ The notion that medical care was no longer a privilege of the rich but everyone's basic right, grew.⁵ Doctors were now servants, not lords.

The role of medicine today is particularly under dispute in the care of the gravely ill and dying. The AIDS epidemic has made the general public very skeptical of established medicine.⁶ In these cases, recourse to medicine seems to be the only possible avenue before the spectre of death. Consequently, our society massively confides the care of the dying to medical institutions. Here begins the confrontation between the partners at the scene of death: the patient, the family and medical personnel. Medical personnel are hampered by their inability to accept death with the result that, when the final stage is reached and they are without resources to fight the inevitable, some of them come to the logical conclusion of euthanasia.⁷ It is in these institutions that death imposes radical limits and is always without response or answer. This terminal situation confuses and confounds medical thought (and aspiration) as it has developed over the past 40 years, where personnel have been taught that almost nothing is impossible.

It is in these institutions which care for the constant stream of the dying (e.g., AIDS victims), where the illusions of medicine begin to unravel and will continue to unravel rapidly as the AIDS epidemic becomes more pronounced. Medicine had hoped to be triumphant before a public which had declared itself saved. Its caretakers had been, up to this point, untouchable and the most respected of professionals. In the face of death, we have again discovered suffering and we speak about it more openly today. In the face of the suffering of death, medical personnel have become more human, more limited and appear neither as god nor as devil. They appear as groping, confused and pain-filled as the rest of us in the face of overwhelming death. In the presence of this suffering and dying, medical personnel are also people who are suffering.

Burnt-out Syndrome

Medical literature, consecrated to the suffering of medical personnel in the face of constant death of their patients, is not abundant. This is not

strange, since the spectre of young people dying en masse did not really begin until 1985. This phenomenon will increase exponentially each year from now on. Between 1977-1985, few articles were dedicated to this topic. Nothing appeared in magazines of general circulation; neither did this kind of study appear in the more technical journals of oncology and gerontology. The only thing that comes close are the specialized studies which seemed to further separate doctors from nurses.⁸ M. Vochan did a study-questionnaire to measure the stress level of nurses who dealt with dying cancer patients. She established the fact that their stress was twice as high as that of fellow nurses in units of the *same* hospital and was only a little less stressful than that experienced by women recently widowed.⁹ E. Leara examined in detail symptoms of medical personnel who cared for the dying. The study was done after the death of their patients. The results were as follows: fatigue, migraines, breathing problems, insomnia, lack of appetite, all characteristic of one of every two nurses she studied. In addition, from a psychological perspective, these medical personnel had recurring thoughts about the deceased patient, a feeling of powerlessness, crying, a sense of shock, disbelief, defeat before a complete loss, difficulty concentrating, anger, anxiety, and irritability.¹⁰

There is enough evidence in this medical literature, while not overwhelming, to conclude that the death of patients occasions a real mourning in those who survive, including health care workers and professionals.

E. Millerd and S. Sanfield, in their study, go even further and define health care professionals as survivors of multiple mourning.¹¹ Millerd compares them with the survivors of concentration camps and sees in them a real "survival syndrome" which describes their close experience of death. According to him, death becomes inseparable from the thoughts and bodies of the medical personnel. They have the feeling of guilt by living at the price of the life of another, like survivors of battle. They are happy to be alive, but they also feel guilty because of their survival. This fills them with anxiety. They try to fight all this by reducing their capacity to feel and think. This can go as far as an identity crisis. The attempt is one of emotion control.

Line of Thought Repeated

This same line of thought is found in each of these authors. Faced with repeated loss of patients who are confided to them through death, these health care professionals feel major distress which gives rise to psychological symptoms. Freudenberger, invented the concept of burn-out syndrome to describe the final stage of a professional who is completely destroyed by his work, that is, the one who is incapable of carrying on his/her work.¹² The health care worker is used up, burned out, consumed by his/her work. This syndrome is a kind of nervous depression (or its somatic equivalent which finds its source in the stresses of his/her

work). Burn-out is an identity crisis in which his/her professional identity is badly experienced by the individual. This makes it impossible — at least for a while — to continue the work which has brought about the trouble in the first place.

To be sure, there is an equivalent in this burned-out syndrome in other professions which have nothing to do with the care of the dying. But with health care professionals, the cause is not just psychological; it lies at the heart of the human question itself — the meaning of life in the face of death. In other words, there is a question here without a response. The problem and question of death can know no solution, at least from a medical point of view.

Existential Suffering

It is common for a health care professional, during the same day, to be confronted with contradictory requests from those who are dying, because they themselves have ambivalent feelings about their condition.

A patient may ask the professional not to continue useless or painful treatments so that he/she may go quickly and quietly. Another, agitated and aggressive, will continuously call her to alleviate his pain, to “do something,” to “heal me.” His painful dying and anxiety weighs heavily on those around him, making them feel guilty that they cannot heal him or help him in his pain and agony.

The health care professional experiences two kinds of pressures: on the one hand, she must be present and efficacious; on the other hand, she must sometimes abstain from treatment and show discretion. This dyptic is a great emotional drain. The health care worker is conscious of the legitimacy of the patient's demands made of her, of the importance and urgency of her responses. Thus, she finds herself with no possibility of retreat, a prisoner of the situation. There is no exit.

When she thinks of the protagonists of such a day, the health care professional can identify with each of her patients and she knows that each was right. She prefers not to think of it at all or to simply forget her work by leaving it behind each day. She lacks a scale of values which would permit her to think about her proper role. She does not know how to distinguish what is good from what is bad. She is troubled, but does not know how to work out her troubles and her frustrations. Above all, she does not know how to work out her pain and despair when all of her patients finally die, one after the other, inexorably. This is doubly unbearable when most of them are young, as is the case when working with AIDS.

Hence, these health care professionals refuse to face death in the dying who die in a continuous stream and who impose pain-filled relationships on him/her, creating great pressures. These are multiple relationships which are, at once, simultaneous, obligatory, repetitive, immediately decisive — all of which maintain her in a continuous and chronic state of

emotional and spiritual drain and exhaustion. Fascinated by the mysterious and unknowable character of death, deprived of solid pivotal and directional moorings, these medical personnel undergo — without any possible flight or retreat — all the difficulties of thought: confusion, impossibility for reflection, thought and memory.

After having considered the psychological manifestations of the suffering of health care professionals, we must examine what is specific to them: the absence of any preparation or orientation in the face of death. We must now listen to the institutions of care in which these health care professionals work.

Therapeutic Despair: The Institution

The health care worker calls out to others to help his/her dying patients. There must be something someone can do. Exhausted, depressed, unable to accept the death of her patients, what she unconsciously desires is to be unburdened of these dying people, discharged from the problem and the responsibility which he/she cannot understand or deal with.

It is, therefore, the institution itself which is in crisis. Incapable of assuming the difficulties of the task and conscious of the impossibility of sustaining its own members, it cannot find in its own resources — ideological, medical, philosophical and technological — the means of treating the problem which it cannot ignore because it is always present: death.

Consider the absenteeism of nurses who work with the dying.¹³ It increases after painful deaths. The instability of health care workers themselves is very great, characterized by delayed response time and frequent requests for transfer. Various practices betray the same attitude: exaggerated and repeated lab work, explorations and diagnostics — these are all defensive mechanisms as much as medical prescription for drugs or surgical interventions.¹⁴ They are all the paradoxical signs of therapeutic powerlessness. The medical ideology which has sustained these workers has failed them and errors, tears, and conflicts multiply. Personnel are anxious, guilt-ridden and aggressive; they are in a state of constant and rampant depression which, in turn, feeds institutional depression.

This is certainly true of nurses and doctors who treat many AIDS patients on a long-term basis. These numbers will increase exponentially in the years ahead. Since duty to and care of these multiple dying people is obligatory daily, almost all the professionals are in a situation of burn-out with the risk of chronic depression.

The chief consequence of this state of affairs is what can be called the state of therapeutic despair. Being always preoccupied with patients, the great majority of whom will not survive (cancer, AIDS), the medical professionals begin to doubt their capacity to save their patients. This gives rise to a sort of constant despair, not so much because of the death of the patients, as because their death comes about only after long attempts to

save. It is a loss and a mourning which are lived as failure. All this brings into question the meaning of the whole therapeutic enterprise: "Why do anything, because they are all going to die anyway?" All these efforts — medical and relational — seem to be instants which have no meaning, and health care workers begin to seriously doubt interest in their own work.

In order to protect themselves against these feelings of uselessness, failure and loss, medical personnel are tempted to consider this suffering of dying people as banal and without importance, necessitating no reaction or commentary, no words — nothing which would recall meaning or the gravity of the situation or the solemn character of what is transpiring.

Henceforth, the deceased lose their status as unique human beings in order to become dead among numerous other dead people, whom everyone has long since forgotten. There is only a system of organs whose function has ceased: "Number 12 had a hemorrhage and died." Number 12 has ceased to be a human being and is now a number, a stomach, a tumor. In that way, the professionals need no longer feel, but now they are condemned to silence or worse, they are vowed to despair which cannot afford to be recognized because these deaths are repeated almost every day.

After they have divested their patients of human dignity, health care professionals finally come to divest themselves of the dignity of aiding the dying and living up to the highest standards of their professions, thereby divesting the institution of a source of professional satisfaction. They develop a feeling of social uselessness, chronic failure and guilt.

To hide and control one's emotions becomes an imperative: their existence or importance are denied. All questioning is abandoned and nothing is a problem any longer — neither death, nor suffering, nor the constant spectacle of degradation, not even the practice of euthanasia to which the despair and the desire to flee have naturally led.

At this stage, the idea of service is turned toward research tasks. We expect medical progress and in its name; it is imposed on patients. The accent is placed on sophisticated explorations and therapeutic attempts. In brief, it is the ideology of medical science as the sole means of conquering suffering and death. Unfortunately, the patient can suffer from all this and become an object of experiment more than a subject who suffers. The relational dimension of care is neglected and this seriously contributes to a division among health care professionals. Nurses who must carry out all these painful procedures feel used by the doctors and the institution without doing any good for their patients or for themselves, for the matter. The doctors feel that the nurses are not scientific enough, lack rigor and are not dedicated to the scientific project. The division is then complete. Ideology separates rather than unites and the institutional crisis only increases.

Hence, there are great difficulties in mixing harmoniously both science and relationship to the patient as therapeutic tools. Death serves as a revelation. Death questions medical practices; it also forces health care professionals to painfully rethink the concept of care, the place of

medicine in society and its conception of man. In perspective of death, what is society's demand from the world of medicine? Does medicine even have the means of answering this question?

The Testing and Travail of Medical Professionals

Clearly, the problems posed here are not just individual problems, or even psychological or medical problems.

We frequently hear that a person died quietly, without pain, in no agony, with his/her family around him, helping him, surrounded by health care personnel. In short, such a person died a "good death" (whatever that means in the final analysis).

But if we were to ask those health care professionals about what they did, many would be sad (which is normal); in addition, they also would feel guilty because of death, which they consider to be a failure, which is curious.

This feeling of failure in death results from their desire to combat suffering and death. Yet, it is not just a question of feeling guilty for having survived; or that he/she is relieved that the other died (and not me); or even the guilt for desiring the death of this sick person. Ambivalence is not the problem — it's something else. It is the feeling of having been conquered by death and not having maintained an all-out effort to defeat death. As we have seen, this plunges health care officials into a feeling of personal depreciation and failure in their professional task. Not only is their work no longer a personal source of satisfaction and enrichment, it now becomes the place of self-hatred while, at the same time, there arises a questioning of all the reasons (conscious and unconscious) why he or she chose this profession in the first place. Just like their patients who are often persuaded that their lives have no meaning or value and are thereby submerged into a state of melancholy, so, too, do health care professionals often come to consider their efforts to be vain and they find themselves menaced by the same kind of melancholy as their dying patients.

How can "being there" (which even the dying consider to be a great help and consolation) be considered a failure by these professional men and women, and even cause them to suffer? It is normal that they reproach themselves for not having done enough. But is the failure of medicine in the face of death (which always wins) the failure of health care professionals as well?

This is an important question because the feeling of "never having done enough" is precisely the feeling that has urged these professionals on to greater heights and dedication in the past. In the face of vast numbers of dying people, it is this feeling which is destroying health care professionals.

The worst possible scenario is not to be content with treating pain, but to give in to the temptation of euthanasia. Euthanasia is an escape from pain to a "good death" which is at least desired and mastered. We are in control with euthanasia.

The best scenario is not where death is considered to be a failure but rather a normal part of human life.

In both cases, it is the way one dies which replaces death in the preoccupation of the medical personnel. Both practices attempt to help in bringing about a peaceful death. The problem with the people who advocate euthanasia is that they see death as a good! Death is never a good; it is an evil even when consciously desired. The whole history of western medicine has always seen it as an evil to be fought and struggled with, even though it always won in the end.

The real question is this: when death approaches, when all hope of recovery is gone, can we do any more than "be there" with the dying patient? This is the very heart of our problem.

The Promise of a Good Death

To bring about a "good death" for one's patients is a generous idea and a laudable objective of the health care worker. But is it a promise anyone can really keep? Such a "good death" is really an illusion, a useful illusion which helps us fear death less, but an illusion, nonetheless. Death is an evil always and while sometimes welcome, it is evil, nonetheless. To die without pain, to be separated from life, from loved ones, to face the unknown — this is what death is. It is an irreducible trial, unique to each person, generator of sadness and fear. To therefore treat death as a problem for which we seek a solution is to do false research. Death is always an inevitable and sometimes painful end. Such a demand on medical personnel is impossible to fulfill or satisfy; it only generates feelings of powerlessness and uselessness.

Within the scientific community everything happens as if there were a belief (never formally articulated) which holds that little by little, science and technology will resolve all problems which are not solved today. Those whom we cannot cure today we will cure tomorrow. It is all a question of means, time, work, resources and research. One hears this all the time about AIDS, as the evidence of death overwhelms us each day.

But by saying this, medicine is unconscious of the fact that it develops an illusion of omnipotence for a future where it will abolish pain and finally cure death itself. In such a view, death is no longer a natural limit but an avoidable accident. This makes health care workers feel great guilt when their patients do, in fact, die because, according to this ideology, they aren't supposed to die.

Our society will no longer tolerate pain, suffering or death. In an increasingly peaceful world, every problem has its technician, its specialist and its solution. We turn to medical personnel and we demand of them not only that they abolish pain but also suffering, doubt and mourning. This is a new, unrealizable task and a new source of suffering for health care professionals which no one had to face before.

The medical institution, therefore, is always situated this side of what

our society expects of it. Powerless to satisfy the incredible and unrealizable demand of the public to heal death and abolish suffering, medical personnel suffer profoundly for an ideal they can't ever reach.

Today the suffering of medical personnel is not only the result of psychological stress but the result of a realization of a basic reality — the brutal recollection of limits of every human endeavor. It always suffers in a world which desires no suffering. This suffering is transferred to medical personnel so that the dying do not suffer. Nor is it a shared suffering because no one else wants any part of it. Medical personnel must experience this suffering in solitude.

To see the suffering of health care professionals as a rich sign and symbol of meaning is to modify the whole medical enterprise. We cannot abolish suffering and death; we can only take account of it and, without masochism or complacency, try to accept the fact that it endures and sometimes submerges us.

Death remains suffering no matter what we do. It is from this certitude of death that the notion of "being there" is born. "Being there" is not a solution to our problem (humanly speaking, there never can be any), nor is it a therapeutic technique of care, but a rite of passage which is both separation and loss, affirmation and preservation of the identity of both the one who passes and the one who helps him pass. This companionship with the dying permits us not only to think about the unthinkable mystery of death, but to think about the suffering of knowing that we, too, are mortal and that we, too, must die. Maybe dying persons frighten us so because they remind us of what we all will inevitably be.

A solution to the problem of death is beyond medicine and technology, beyond all present and future. Medical personnel can only show solidarity, concern, care and love by "being there" for those who have reached the end of the human condition, close to the one who dies, as he/she enters the mystery of eternal silence. This is the very limit of the human endeavor to which medical personnel are called to serve. The pain and the suffering of loss and separation are part of the human condition itself which we all share. To be there with the dying is to love the dying and, also, to love ourselves who share with them the same human morality.

References

1. Aries, P., *The Hour of Our Death* (New York: Knoff, 1981), pp. 7-14.
2. Illich, *Medical Nemesis* (New York: Viking, 1983), pp. 10-18.
3. *Ibid.*, p. 24.
4. See the encyclical letter of Pope John XXIII, *Pacem in Terris*, par. 11.
5. See the furor created by Masters and Johnson in their book *Crisis* (1988) on the effects of the AIDS epidemic on heterosexuals. A summary of the book appeared in *Newsweek* (March 7, 1988).
6. See the reaction to a small, anonymous article which appeared in *JAMA* for March 1, 1988 about a resident who killed a dying woman who suffered from terminal ovarian cancer.

7. See studies in the magazine, *Death Studies*.
 8. Vachon, M. *et al.*, "Measurement and Management of Stress in Health Professionals Working with Advanced Cancer Patients" 1 *Death Education*, pp. 365-375 (1978).
 9. Leara, E., "Grief Among Health Care Workers," 37 *Journal of Gerontology*, 604-608 (1982).
 10. Millerd, E., "Health Professionals as Survivors," *JPN and Health Services* (April, 1977), pp. 33-37; S. Shanfield, "The Mourning of the Health Care Professional," 4 *Death Education*, pp. 385-395 (1981).
 11. Freudenberg, J., *Burn Out: The High Cost Of High Achievement* (New York: Doubleday, 1980).
 12. Millerd, *op cit.*, *supra*, note #10, p. 36.
 13. *Ibid.*, p. 34.
-