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Terminal Patients in Holland

K. F. Gunning, M.D.

The following paper was presented by Dr. Karl Gunning, president of the World Federation of Doctors Who Respect Life, at the Medical-ethical Congress in Slavonski Brod, Yugoslavia, in November, 1990.

We mention the contrast between humanitarian ethics and utilitarian ethics. In humanitarian ethics the patient is the center of all our care and the patient's life is respected from conception until death. In utilitarian ethics questions of usefulness enter into consideration. An unborn baby may be killed for the sake of his mother; patients and handicapped people may be killed when they become a burden to society.

In this paper, I would like to mention two ways to deal with terminal patients, euthanasia and real care as it is given in the so-called hospices in England. The second way is clearly an expression of humanitarian ethics. The first way I call utilitarian, even when euthanasia is given at the request of the patient.

What is euthanasia? Originally it meant dying a good death. In Holland today, it means deliberate killing of a patient by a doctor at the patient's own request. So if this is the real meaning, we should talk about deliberate killing, rather than using the disguising term "euthanasia".

We in Holland have been very near the point where the law would have made it possible for a doctor to kill a patient at the latter's request without being prosecuted. Our government had introduced a bill which should have been debated in our Parliament in April last year, but two days before that debate was to start, the government fell and the bill was withdrawn. Our Dutch Doctors' League for the Respect of Human Life had made an eight-page paper on the consequences of allowing doctors to kill patients, which was sent to the Queen, all Cabinet Ministers and members of Parliament, all judges, doctors, priests, clergymen, etc. Many insiders have told us that the bill was withdrawn as a result of this action.

Unfortunately this has not made much difference in reality, as deliberate killing was already committed by Dutch doctors on a large scale and has continued to be applied with hardly any hindrance. The fact is that for a number of years, our courts have decided to waive persecution of doctors who kill patients, provided they obey certain rules. The doctor should tell the patient the real nature of his disease, his chances of recovery, what suffering may be expected. He should ascertain that the patient himself wants to have his life ended and that this request is maintained. He should consult another doctor. He should keep a record for the public prosecutor, etc. We should, of course, keep in mind that after the patient's death, the

chief witness is no longer present, so that he cannot deny any untruthful information in the doctor's report. So the court is unable to verify whether these rules are obeyed or not.

How Often is Killing Practiced?

How often is this killing practiced in Holland? Nobody knows exactly. The estimates by the advocates of legalization run from 6,000 to 18,000 per year, that is between 5% and 15% of all deaths, as the yearly mortality in Holland is near 120,000. Yet only slightly more than a hundred cases a year are reported.

How often do patients ask to be killed? That is another question. Here the estimates are between 2,000 and 3,000 times a year which would mean that in the majority of cases, patients are killed without their request. If this is true, it means that euthanasia in Holland is not so voluntary as many people believe.

What are the reasons for killing a patient? Usually there is unbearable pain, which means that the doctor is not well-informed about effective analgesia. Or the patient fears being a burden or looking revolting. But economic reasons, both in the family and in the national health offices cannot be ruled out.

One doctor, who discussed with me his conviction that many patients die as a result of an overdose of morphine, suddenly remembered a case in his own practice, where an elderly patient was terminally ill and his son, who had arranged a holiday, had asked this doctor to end his father's life before his departure, because he could not interrupt his holiday to attend the funeral. The doctor gave his patient a huge dose of morphine, but when he came back to ascertain his death, the old man was sitting happily in his bed: he had not had such a painless day for quite some time! Apparently the doctor did not realize that this was not killing at the request of the patient himself.

The present government has decided to postpone any legislation of euthanasia, as it first wants to know how large is the demand for it in reality. It therefore has installed a committee to investigate more accurately, how often euthanasia is practiced.

In the meantime, a lady who had been in coma for over 15 years, was left to die by withdrawing food and fluids, but the doctor was not prosecuted, as food and fluids were administered by gastric tube, which the court considered to be a medical act, which the doctor was free to stop as being senseless. Here again the death was not requested by the patient but by her husband. Nobody knows whether the patient suffered at all, or whether she suffered from her comatose state or on the contrary, whether she suffered from being starved. In fact, the court has ruled that the doctor is free to cause the death of a patient without his or her consent, when the doctor considers the patient's life to be senseless.

Patient's Consent Not Required

Though euthanasia in Holland is presented as a merciful act, entirely performed for the benefit of the patient, we see already now, before any legislation has taken place, that the request or consent of the patient is no longer required and that utilitarian motives have become the deciding factor. And even if the patient himself asks to be killed, it may be the doctor's own fault, because he failed to treat the distressing symptoms adequately. Killing the patient instead of treating his symptoms seems to me not merciful, but utilitarian: giving in to the patient's request seems to be more easy than to find the effective care.

This is the present situation as regards killing by doctors in Holland. We did win a victory, as legalization was prevented, but we have no reason to relax and stop our activities. On the contrary, we still have a long way to go.

What is the course of action indicated by humanitarian ethics? Fortunately we have a great opportunity to start a positive action. Some time ago a governmental committee reported that Dutch doctors in general do not sufficiently know how to deal with pain in terminal patients. An inquiry showed that in 53% of cases with cancer and pain, pain control was inadequate, with the result that the patients suffered pain unnecessarily. According to this committee the main reason was fear for the side-effects of opioids, which caused the doctors to prescribe these drugs in too small doses, and only a few days before the patient was expected to die. The committee suggested that instead of killing patients with unbearable pain, doctors should be better trained in effective analgesia.

This year I had the opportunity to get one month's training in the theory and practice of palliative care at St. Christopher's Hospice in London, the first hospice that was built especially for the treatment of terminal patients. It was founded in 1967 by Dame Cicely Saunders.

Hospice Policy

The hospice philosophy starts with the recognition that in a terminal patient the disease is incurable, but that pain, nausea, shortness of breath and other distressing symptoms need to be carefully examined and adequately treated. Though a doctor might be tempted to say: "There is nothing more that I can do for you", this is actually the time when the patient needs his doctor most. The doctor should be available and ready to spend as much time as is needed.

In St. Christopher's Hospice the patient was first of all given the feeling that he was most welcome, that he could talk freely about all his complaints, which would be taken seriously and treated as well as possible. Then each one of the distressing symptoms was investigated.

Let us first take the symptom pain. It can have five or six different causes, each of which will need a specific treatment. In each case of pain the cause or the different causes should be carefully determined and the treatment should be chosen accordingly. The next thing is to give an adequate dose

and to give this dose so regularly, that the next dose is already effective before the pain comes back. The patient should be completely without pain 24 hours per day, seven days per week. If the patient is still in pain after the initially established dose, the doses should be increased subsequently until there is no more pain. But pain is often aggravated if the patient is also anxious and tense. It is very important to find out the cause for this anxiety and to give the patient the feeling that he can trust and relax. He may have worries about his family or his job, or he may want to confess to his priest or to settle his last will. All these problems and fears may influence his level of pain.

One of the major discoveries of the hospice movement is that morphine is not the dangerous drug we were taught it was, but indeed a very good analgesic, provided we know how to use it. Apparently our body contains substances called endorphines which have a structure very similar to morphine. In some cases of chronic pain, such as in cancer, the amount of endorphines is diminished. If the right dose of morphine is given, just enough to replace the loss of endorphines, the pain disappears without any side effects. But if morphine is given to a person who is not in pain, or if more morphine is given than needed, then side effects may occur such as drowsiness, respiratory depression, addiction, etc. The way to find the necessary analgesic dose is, roughly speaking, to double the initial dose every day until complete analgesia is obtained. But, as said before, we must first ascertain the cause of the pain, as in some cases of pain morphine is not the adequate drug. In the case of brain or liver metastases, Dexamethasone must be given. In some cases nerve block or a spinal catheter is necessary, etc.

Treatment According to Cause

In the same way, nausea or vomiting can have different causes and should be treated according to the cause or causes. Diarrhea, constipation, itching, bed sores, shortness of breath — all these symptoms need to be carefully examined and taken seriously, so that the patient can be comfortable and relax and live as normal a life as possible until the day of his death. The patient should be carefully informed about his condition, unless he indicates that he does not want to know. But in most cases the patient is quite willing to accept his death as unavoidable, and he is far less afraid of dying, as his symptoms are well taken care of. Sometimes the patient does not want to talk about his problems with his doctor, but likes to speak with another member of the staff — a nurse, the physiotherapist, the social worker, etc. Actually everybody in the hospice was willing to spend time with the patient at his request. During the course, the importance of close teamwork between doctor, clergy, nurse and social worker was repeatedly stressed.

Once the symptoms are under control, the patient is allowed to go home, if this is possible. Sometimes the family cannot cope all the time with the

patient at home, so he may need to stay one or two days per week at the hospice, so that the family can relax and look after their own affairs. For that purpose most hospices have a day center. Sometimes the patient can only go home a few times a week. But as long as the patient is at home, he will be looked after by a district nurse from the hospice and at any time of day or night the patient may call the hospice, if he is in trouble.

At the same time, each member of the family or the significant friends should be contacted to know if they need help or are able to offer help themselves. This is usually the task of the social worker, who can inform the doctor if help is needed. When the family and the patient have accepted death as the conclusion of a time of sufficient and adequate care, there usually is far less feeling of guilt and anxiety, so that the period of mourning after the death is less burdensome and protracted. Usually the family is very happy about the way the patient has been cared for, so that they talk about it with their friends and like to contribute time and money for the maintenance of the hospice. Most hospices in England are charities, which means that they offer their services without being paid, and are supported financially by volunteers in the neighborhood. Sometimes the local National Health System gives a contribution in recognition of the help which the hospice is offering to their patients.

Let me give one example of a patient who entered the hospice with the request to be killed, because she could no longer stand her shortness of breath. The admitting doctor told her he could assure her that she would breathe more freely after one or two days. He said that this hospice never killed a patient. But suppose it did, what would she like him to do? Should he come in with a syringe and tell her that this was the end? Or should he do it secretly without her knowing? She began to laugh. She did not want to know when the deadly injection would be given, but of course she would think of every injection that this was the final one. But, if she could again breathe normally, she did not want to die anyway.

Attempts to Start Hospice Care in Holland

Already some attempts are being made to start a similar hospice care in Holland. We hope this care will eventually be available throughout the country, and that people will realize that this is the correct way to help our terminal patients instead of killing them. We hope that our government and our courts will come to the same conclusion, so that the trend to accept euthanasia will be halted and that we will return to the old practice, where everyone's life is protected by the law and respected by the doctor.

We must decide whether to accept humanitarian or utilitarian ethics. We cannot have both at the same time. In this respect, it is interesting to compare the instructions for the heads of departments in a Swedish hospital in 1940 and in 1972:

In 1940 the instruction was: "It is the duty of the head of the department . . . himself to treat those in need of care with kindness and humanity

and to urge the staff he is head of to fulfill their duties to them with tender consideration.”

In 1972, in the same hospital, the instruction was: “It is the duty of the head of department . . . to be responsible to make effective use of hospital beds, staff and equipment of the department . . . the staff carefully performing their duties . . . making sure the organisation is run as economically as possible.”

In 1940 the patient was the center of hospital activity; in 1972, the duty was to make effective and economic use of the hospital facilities; the patient was not even mentioned any more. Of course the issue is what the patient himself prefers. The patient, that is you and me. We can decide what should be the ethics of our doctors and nurses. We do not have to leave our countries forever under the dictatorship of utilitarian principles.
