



2. Medical ethics and the treatment of patients with incurable diseases and futile treatments

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Background

In recent years, as chairman of the Ethics Bureau, I have been asked several times by senior doctors if we have an ethics position paper with guidance on how to treat children, the elderly or any patient suffering from an incurable disease? The automatic response was that in every medical issue one must first rely on the professional knowledge in the field, and make decisions according to what is accepted from a professional medical point of view.

The dilemma presented to me by the doctors was due in part to a feeling of compassion for the patient. Quite a few have pointed out to me that the medical decisions made when they come to treat patients with incurable diseases, and the recognized treatments for these futile conditions, are sometimes made for unrelated reasons.

Sometimes the decision-making involves considerations of fear of lawsuits; over-responsiveness to strange and unprofessional requests of family members or relatives accompanying the patient; difficulty breaking the bad news to the patient and his loved ones, which may cause practitioners to continue treatment that is known in advance to be futile; blurring the line between the patient's autonomy and the doctor's professional decision-making; creating illusions, some of which are the result of surfing the Internet, since the patients and their relatives are looking for information that will help them understand the disease, hoping to find the "magic potion" that will heal their loved ones; promises of "life-saving" drugs, a commercial definition that sells expensive drugs but lacks professional content; loss of trust in the professionalism and good intentions of the doctors. All these and more result in tests and treatments which we know do not help prolong life and may even harm the quality of life. It is inevitable that due to the side effects, certain actions may even shorten life expectancy.

The futile investigation and treatment infringe on the patient's right to arrange his affairs before he is unable to do so and deprives his loved ones of the right to say goodbye and continue their lives properly.

The law in the State of Israel prohibits euthanasia, and it is currently a criminal offense. This position paper does not support euthanasia. **In our preliminary discussions, we dealt with the understanding and recognition that sickness and death are a chapter in human life, and we should not close our eyes and ignore these difficult human experiences.**

We found that in Israel, as in other countries in the world, there is an increase in the proportion of doctors who are willing, on one hand, to accept euthanasia in its various forms as a therapeutic option, and on the other hand - doctors who continue to perform



futile treatments, which may cause suffering to the patient without benefit, tests and treatments about which it is not clear whether they are life-prolonging or life-shortening. This is why the issue came up for discussion in the Ethics Bureau.

The discussion and the position paper obviously respect the group of patients defined in the "The Dying Patients Act", who request that certain operations not be performed on them. When the patient can still express his wishes, or parents in the case of a child, or the continuing power of attorney that the patient has appointed on his behalf to make his decisions when he will not be able to express his wishes, joint therapeutic decisions can be made. The problem is exacerbated when we do not know how the patient sees the continued management of his illness, and the family expresses its wishes, and sometimes we hear conflicting wishes of different family members, which do not necessarily represent the patient's opinion.

A common occurrence, unfortunately, in hospitals is to see doctors going to check with the family "Should CPR be performed?", or more precisely - should a tube be inserted into the trachea in order to respire a person at the end of his life, when every knowledgeable doctor knows that doing so will not produce benefit, will not prolong life and certainly will not improve the quality of life. An illusion has been created among the general public, as well as among caregivers, that every person must undergo intubation at the end of his life. This is a professional medical question, the answer to which must take into account the patient's medical data and his current illness, and not be left solely to the choice of his loved ones. Opportunities and risks must be weighed, just as they are in every decision concerning an examination or treatment intended to ease the patient's suffering and prolong his life as much as possible.

We must remember that the word "resuscitation" to the average person means bringing a dead person back to life. A family that has to answer such a question will usually say yes, if only because they may be mistaken and think that by answering "do not perform CPR" they caused the death of their father, mother or any other dear person. Respiration does not always prolong a person's life, and under certain conditions may even be considered harmful because the benefit does not outweigh the pain and discomfort caused to the patient. In addition, the unnecessary and inefficient use of facilities, equipment, etc. may harm other patients for whom the treatment won't be available, although if it were available they would recover. This violates the principle of "distributive justice". Professional judgment should lead the doctors to the right decision- if one is talking about respiratory aid for a short period while the patient overcomes a medical problem, there is no doubt that it should be given. However, if the procedure will not solve a medical problem, and possibly cause death - there is no justification to perform it.

Additional examples include: the continuation of oncological treatments, when there is damage from side effects and no effect on the malignant tumor, or an operation which will not succeed in solving an incurable medical problem, all in accordance with the medical



ethical principle "first do no harm".

And it goes without saying that when there is a fear that the very treatment will shorten the patient's life - it must not be performed.

Palliative treatments should be incorporated in the treatment of these diseases, the purpose of which is not to cure the disease, but to relieve the symptoms from which the patient suffers, such as pain, nausea, repeated vomiting and sleep disturbance.

It is hard for us mortals to come to terms with death. But illness, dying and death are an inseparable part of life. Every second of a person's life is precious, and the doctor's job is to prevent suffering and allow the patient and his loved ones a respectful farewell when he reaches the limit of his professional ability.

A major problem faced by doctors is the fact that in some diseases it is difficult to impossible to determine when the patient is incurable.

After a long and in-depth discussion, the members of the Bureau decided:

1. The doctor, and the patient with an incurable disease, will discuss the patient's aspirations and expectations from the treatment against the realistic capabilities of medicine, and will define the goals of the treatment.
2. The doctor will consider and decide on the most correct investigation and treatment for the patient, according to current guidelines in the field of his medical expertise, professional knowledge and experience as a doctor. In doing so, he will weigh benefits against unwanted side effects. Continuation of ineffective and futile treatment may harm the patient and even shorten his life.
3. The doctor will share the medical data with the patient and his significant others, as early as possible, in order to enable understanding, adaptation to the situation and correct decision-making for the patient. The doctor will refrain from hiding or beautifying the state of the disease and the lack of curative treatment, in order to maintain the patient's autonomy.
4. The doctor will be aware of his own personal values and will ascertain what the patient's values are. In any action or inaction, the doctor will be aware of these considerations when making decisions regarding a patient with an incurable disease.
5. The doctor will locate professional contacts from various fields within his work environment for regular consultations. Consultation is especially important when there is a mismatch between professional considerations, the patient's requests and the doctor's personal values.
6. The doctor will strive to encourage fundamental decisions regarding the treatment of the incurable disease so that these are made ahead of time, by the patient and his caregivers, when there is still time to think first, before hospitalization.



7. When a doctor is treating children, his loyalty should be first and foremost to the child. At the same time, the parents are the caregivers responsible for the child, and it is important to treat their suffering with extreme sensitivity. (In exceptional situations, where the doctor fears that the guardians are not serving the best interests of the minor, legal measures must be taken).
8. The doctor will refer the patient to treatment that improves quality of life, when other treatment is futile (i.e., palliative treatment, as required in different situations).