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Management of the hopelessly ill patient: to stop or not to start?

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Abstract

The paper discusses the subject of futile treatment in the case of a hopelessly ill patient.

The topic has many facets, among them the ethical precepts of preventing futile treatment, but also the economic and logistic impact of treating patients who do not have a fair chance of benefitting from managing their medical condition.

A 75-year old patient, suffering from an advanced stage of Alzheimer's disease and a clinical picture of acute surgical abdomen, is presented and two approaches are discussed.

The first scenario is the aggressive management, including immediate laparotomy and admission to an intensive care unit, a solution without a fair chance of saving the patient's life. The most favorable, but theoretical, output in this case would be the patient's return to his previous mental condition, without any connection with the reality and surroundings and in permanent need for help, supervision and assistance.

The second option is letting the patient die in dignity, alleviating pain and surrounded by family.

The role of the primary care physician and family is discussed and some ethical principles are presented in order to emphasize the importance of preventing futile treatment in a case of a terminally ill patient

Keywords: hopelessly ill, ethics, futile treatment

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Introduction

The average anesthesiologist is often put in a situation in which his/her patient condition imposes a decision related not to the various possibilities of management but mainly in connection to the ethical precepts of the profession.

This kind of situation can happen not only in the cases of patients whose medical condition is above the existing management solutions, in which the conclusions would be obvious, since medicine cannot solve all situations.

The problematic aspect of patient medical condition becomes evident when, from the theoretical point of view there is a treatment, but due to a patient specific situation, this treatment could be considered futile.

The cumbersome reality is today evident more than anytime since modern medical equipment and therapeutic techniques offer a large range of solutions for maintaining the patient alive. The new technology today can keep a patient alive for an unlimited time, in spite of the fact that the his/her quality of life is beyond the lowest limit ethically and morally accepted.

This paper will deal with the ethical aspects of clinical situations in which, theoretically, the patient could benefit from a therapeutic solution, but this treatment would only prolong a life which lacks any human significance.

The case

A 75-year old patient was taken by ambulance to the emergency department (ED) of a general hospital.

His current medical condition comprised cardiac failure, coronary ischemic heart disease, hypertension

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and mild chronic renal failure. In addition he suffered from chronic obstructive lung disease due to heavy smoking, some 25 pack-years for more than 50 years.

The patient had spent the last six years in a retirement home, and four years before he had been diagnosed with progressive Alzheimer's disease, so that in the last couple of months he had not been able to recognize either people around him, or his own family. He was bedridden, under permanent supervision and needed to be fed by the nursing staff. Daily medication included enalapril, mononitrate and a mild diuretic.

Three days before admission to the hospital he refused fluids and food and became obnubilated. The day prior to admission the patient was stuporous, had started to vomit, became oliguric and developed a fever, 38.2 C.

The physical examination on admission at the ED revealed an unconscious and dehydrated patient, with a sign of guarding abdomen, especially in the epigastric area, and rebound tenderness. No bowel sounds were heard on abdomen auscultation. The blood pressure was 75/50; heart rate 95, temperature 35.5 C, respiratory rate 35/minute.

A crystalloid infusion was started, a warming blanket covered the patient and oxygen by mask was administered. Soon the laboratory results reached the ED: hemoglobin 16.9 g/dl, white blood cells 18,200/mm^3, BUN 88 mg/dl, creatinine 4.8 mg/dl, sodium 122 mEq/l, kalium 6.6 mEq/l, bicarbonate 17.5 mEq/l, PaO_2 56 mm Hg, $PaCO_2$ 29 mm Hg. Pulse oximeter at FiO_2 0.21 showed a saturation of 85% and 91% under oxygen mask. A plain abdomen x ray revealed free air under the right diaphragm. The bladder was catheterized and 50 ml of very concentrated urine was found.

The working diagnosis was a perforated viscus, most probably a duodenal ulcus.

The surgeon discussed the patient's situation with the family, an emergent surgical intervention was decided and the anesthesiologist on call was asked to prepare the patient for operation.

The first question: is this patient hopelessly ill?

The list of conditions which answer the definition of a hopelessly ill patient would include: brain death, persistent vegetative state and irreversible and very severe dementia, (the so called "the pleasant senile").

The above patient fits the definition, since he was in a very severe cognitive condition, unable to take care of himself, did not recognize people surrounding him and needed help even for the simplest daily activities.

In addition he had reached the hospital in a very severe acute and neglected condition for at least 72 hours. He was in septic shock, with metabolic acidosis and acute respiratory failure. Theoretically, in this situation a completely successful outcome of treatment would bring the patient back to his previous status, but practically his chances to overcome the acute situation are very low, if at all.

Sepsis and septic shock are accompanied by a high percentage of mortality in the intensive care units (ICU) and some data speak about a 50% mortality, even when there is no coronary disease involved [1]. In a recent report on mortality in abdominal septic shock [2], the mortality reached 19% in the group treated with corticosteroids and 25% in the control group.

The association of Alzheimer's disease only aggravates the situation. Alzheimer's disease was the 6th cause of death in the USA in 2010 [3].

If so, in this case we are faced with a question regarding the immediate attitude of the therapeutic team. The question is: to treat the patient aggressively by proceeding to an immediate laparotomy or to consider the surgical intervention as a futile treatment?

What is futile treatment?

The literature is full of studies and reports regarding futile treatment and its meaning.

In the last 50 years some 4000 reports and reviews have been published only in English language journals.

In their classic report, Swisher and Berriman [4] defined futile treatment as "care that neither produces a demonstrable positive effect, nor changes the prognosis, nor improves the patient's quality of life".

Another study defines futile treatment as useless, ineffective care giving with wastage of resources and a torment of both patient and staff [5].

Kalra et al. [6] recognize two kinds of futile treatment ("treatment the medical team feels would not be beneficial to the patient"). The physiological futility includes that treatment which cannot achieve a desired physiological effect, such as antibiotherapy for a viral infection. The second one, the goal-defined futility, implies treatment which has no efficiency regarding the patient's goals, such as restoring previous level of function, survival to hospital discharge or the ability to live independently. They also stress the fact that even successful cardiac resuscitation would not be beneficial in case of cognitive impairment.

Another definition of futile treatment was presented by Dzeng et al. [7] as an effort to provide a benefit to a patient that is highly likely to fail and whose rare exceptions cannot be systematically produced. The authors cited data presenting the effect of futile treatment on the moral mood of the therapeutic team (in this case internal medicine residents), with clear negative effects on job satisfaction, psychological and

physical well being and self image, with consequent burnout and thoughts of quitting the profession.

They also discussed some specific cases, witnessed by residents, the first one being very similar to the patient described above:

"This person with advanced dementia had been in and out of the ICU multiple times that month at baseline and had a very poor cognitive functioning. She had no quality of life. She was septic. I forgot how many other comorbidities on board".

The results of futile treatment have been studied by Huynh et al. [8]. They investigated five ICUs and followed up almost 7000 critically ill patients admitted to those units. In 11% of patients they reached the conclusion that the treatment was futile. 85% of them died in the first six months after discharge and all the survivors remained in severely compromised health status. More than this, the daily cost of futile treatment was found to be higher than US $ 4000.

Schneiderman et al. [9], referring to futile treatment, wrote that just because a treatment has an effect, it does not necessarily benefit the patient.

Finally, a very interesting and provocative item was presented by van Dijk and Sonnenblick [10] regarding the different attitude towards a terminal dementia patient in comparison with any other terminal patient. Applying a futile treatment in case of severe, terminal dementia means a significant prolongation of a life without sense and content, since the survival expectancy, in the absence of any serious comorbidity, is usually longer in such cases.

The implications of futile treatment

The first aspect to be discussed regarding futile treatment is the medico-ethical one.

Here we face a wide range of ideas and conceptions.

Gillon [11] defines medical ethics as the analytic activity in which concepts, assumptions, beliefs, attitudes, reasons and arguments underlying medico-moral decision making are examined critically.

An in-depth discussion of this moral concept would be beyond the scope of this paper.

But the main thought to be underlined here is that which obliges the physician to use his/her moral concept in order to reach a decision in each case a futile treatment is above any controversy.

Differences exist among civilizations and religions.

Gillon emphasizes the fact that medico-moral decisions are those "that concern norms and values, good or bad, right or wrong, and what to be or ought not to be in the context of medical practice" [11].

According to Gillick [12] and Kupfer and Tessler [13] both Catholic faith and Judaism accept the principles of withholding treatment in cases of advanced dementia.

The origin of these concepts resides in the reality which is being faced today.

In most parts of the world the supply of critical care is limited because of scarcity of funds and manpower. Thus futile treatment may present an opportunity cost, defined by Huynh et al. [14] as "the loss of potential gain from other alternatives when one alternative is chosen, if critical care is unavailable for another patient for whom it is indicated". In that study the authors investigated the impact of futile treatment on the availability of ICU beds for patients who could benefit from being admitted to those special units. They found out, during the three months of surveillance, that because of lack of ICU beds and since futile treatment was offered to 11% of their patients, 33 patients had been kept in the emergency department for more than 4 hours, 9 patients waited more than 24 hours to be transferred to the ICU from another hospital, for 15 patients the transfer request was cancelled and two patients died while waiting to be transferred. It is true that the cost of futile treatment days are less expensive than routine ICU treatment (US $ 4000 vs $ 4700) [8, 14], but it seems to be obvious that keeping a terminal patient in ICU and providing futile treatment would affect the fate of other critically ill patients who could benefit from being admitted to a specialized unit.

A study completed some 30 years ago [15] compared the mortality of critically ill patients in two logistic situations: when they had been to an ICU immediately after a severe condition had been diagnosed and when the ICU transfer was delayed because of lack of beds and the patients had been treated in an internal medicine department. Data showed a four time mortality in the second group.

The factors responsible for preventing futile treatment

The first in line should be the patient him/herself. In many countries the legislation permits a citizen to sign up to a living will, in which he/she would be able to specify in which conditions a futile treatment should be withheld. In Israel, in the last years, there is a continuous increase in the number of elderly persons who complete a form in which they express the wish of not being artificially kept alive in case he/she would be in a situation of significant suffering, dying and incompetent. The list of procedures not to be used for artificially maintenance of life includes: resuscitation (including tracheal intubation, cardiac massage, connection to a ventilator), dialysis, major or minor surgery, radiochemotherapy, diagnostic tests, etc.

A study regarding the attitude of the elderly (average age 83) in cases of life support where the patient was in an advanced stage of dementia, Niv et al. [16] found out that more than 80% of responders opposed life-supporting procedures.

Some data show that even if a patient decides to clearly express his/her wish regarding preventive futile treatment, while he/she is fully conscious, patients' views regarding care before they are sick may be different from when they are acutely ill [17].

The topic of the informed consent is a very important one. It implies a very careful examination of the patient's condition and an assessment of his/her ability to understand the situation and the proposed treatment.

But in cases where the patient did not express his/her will while completely competent and alert, what is the role of the family?

The family impact in this situation is cumbersome and debatable. Apparently the close family is supposed to possess the necessary data in order to be able to express the patient's will in case he/she would be in a situation of incompetence. But some data oppose this classical view. For instance, Miller et al. [18] found no correlation between the preference of the patients and those of the next to kin.

In a classical case in court [19] the jury found that the hospital and the doctors were not negligent in issuing a do-not-resuscitate order for a 71-year old comatose patient, over the objection of her daughter.

In a study on dissociation between the wishes of the terminally ill parents and decisions of their offspring, Sonnenblick et al. [20] reported that 40% of the 108 responders declared that they were not able to decide for their parent.

The role of the family in dealing with the incompetent patient or with the absence of an informed consent cannot be overemphasized. In spite of the theoretical situation of conflicts of interest in the same family, it is the obligation of the therapeutic team to contact the family as soon as possible and to offer full information about the patient's status and the various possibilities regarding treatment. The contact with the family is vital in this kind of cases. The team should be ready to answer all questions and even encourage the family to go deep into the patient's medical condition, thus having all the necessary data in order to take a decision regarding the benefit of the patient.

One can imagine how our patient's fate could have been changed in the case where the retirement home personnel had contacted the family a long time before and discussed the required attitude in the case of the worsening of his clinical situation.

The strong cooperation with families is vital for avoiding medico-legal complications. Nowadays, in many countries, there is an evident increase in the number of legal complains against medical institutions and practitioners.

In a case like ours, the danger would not come from the patient himself but where families, unsatisfied with the offered explanations and/or the treatment decisions, could easily contact the judicial authorities and issue complaints regarding the procedure the therapeutic team had decided on to take care of the patient.

Lawyers whose main field of interest is the medico-legal domain emphasize the fact that the number of complaints is high in cases where the family has not been fully explained regarding the patient's condition and did not feel part of the decision making process.

A very important point to be discussed in this context, in the case of a patient unable to decide for him/herself, is the need for appointing a family member who would represent the patient's interest in case there are more than one therapeutic option. In Israel, the court is entitled to decide on such an appointment and this person becomes a partner in the decision making process.

The next to be discussed is the role of the physician in preventing futile treatment.

Needless to say, his role is complex. On one hand, the physician is not always fully convinced by the diagnosis and futility of treatment in every single case. His/her clinical judgment often comes in conflict with the "social-ethical" pressure of the surroundings. The fear of legal liability is also a reality nowadays. Finally the physician is supposed to be fully conscious of the monetary cost of futile treatment and of the fact that keeping a patient in a special framework, such the ICU, would prevent other patients, with real chances to be cured, to benefit from specialized care.

The primary care doctor has a special place in the algorithm of preventing futile treatment. He/she is the first link in a long chain of people and authorities who are involved in this kind of decision. Doulkas and McCullough [21] wrote that the primary care physicians must take responsibility for discussing decisions regarding futile treatments with patients before clinical circumstances call for such decisions. But the primary care doctor's role becomes crucial once the hopelessly ill patient develops an acute condition which, in normal situation, would demand an immediate intervention. Helped by family and by peers, the decision not to send the patient to a hospital and keeping him at home, free of pain and surrounded by family, could be the proper decision. It would avoid the start of a long process, in which it would involve specialists in various domains and where nobody would be sure that the therapeutic team had reached the correct decision.

Finally, it seems that a special role is preserved for the community (according to the principle of "it takes

a village"), in the sense that it is their obligation to create a proper atmosphere by initiating a long process of education at various levels.

The aim of this process is to explain the futility of treatment in cases where the patient would not benefit from a treatment which could be considered efficient in other patients, but completely futile in a specific case.

The concept of "it takes a village" is not restricted to the community itself.

The crucial decision regarding the fate of a hopelessly ill patient cannot belong to one, single, isolated physician. It is to be taken by involving all the specialists who have a say, asking for their opinion, discussing the case, reaching a common and final conclusion and explaining it in the patient's chart.

The medical community, the national organizations of physicians (anesthesiology included) should be involved in this continuous education process. Media should be approached, special situations should be described and public opinion would be involved in an open discussion regarding the fate of the hopelessly ill patient.

Back to our patient

Considering now the options which the physician can select from, it would be worthwhile to go back to the four levels of medical care in acute situations, as proposed by Wanzer in 1984 [22]:

- emergency resuscitation
- intensive care and advanced life support
- general medical care (antibiotics, drugs, surgery, artificial hydration)
- general nursing care

A first, theoretical, scenario for our patient would include all of the above.

The patient would be immediately resuscitated by administering fluids and, if necessary, vasopressors, endotracheal intubation and mechanical ventilation would be started. After stabilizing the cardiovascular condition and improving the gas exchange he would be brought to the operating room, antibiotics administered, the peritoneal cavity drained and at the end of surgery the patient would be transferred to an intensive care unit for further care. There the cardiovascular support would be continued, hydration and nutrition would be assured, and a trial for weaning the patient off the ventilator would be initiated as soon as possible. Physiotherapy, frequent changing of position in bed and management of pain would be added as part of the general nursing care.

The question that would arise from this short description of the management of a septic surgical patient is what are its chances of succeeding.

There is no study which could deal with the answer to this question. But the clinical judgment and experience would give our patient a very low chance of survival. Most probably he would develop acute renal failure, ventilator-associated pneumonia, the weaning off the ventilator would fail, a tracheostomy would be necessary, and dialysis would be started. Finally, the patient would die of a multi-vital organ failure during the first 10 days after ICU admittance. But even if the heroic treatment did succeed and the patient survived his very serious condition, he would be brought back to his previous situation of severe dementia, completely isolated from his surroundings, incontinent and bedridden, needing continuous help for the simplest of daily tasks and activities, such as feeding or walking [12].

A second scenario seems to be more appropriate in this case. The patient would be transferred to the surgical ward, opiates would be administered for alleviating pain, the family would be near him all the time and most probably death would occur in the first 24 hours after admittance.

Wanzer et al. [22] stated that the patients who would require only the fourth level of care, general nursing care for comfort, belong to the category of irreversible illness. There would be no place for routine daily parameters measurements or for any diagnostic procedures. Any surgical intervention should be discouraged.

All these recommendations seem to perfectly fit our patient's general condition.

In most cases the family would need to be convinced that this second scenario is the best for the patient. One has to take into consideration the family stress in the face of the fatal outcome. And above all, this has to be the entire team's approach to the patient's severe condition and the message delivered to the family has to be unique.

Conclusions

The diagnosis of a hopelessly ill patient, meaning that he/she would not benefit at all from treatment, is a subjective one. Beside there is no objective method of assessing futile treatment in a specific patient.

But there is a continuous need to identify both an irreversible medical condition and a treatment which would be futile, because ignoring these kind of situations leads to a series of negative results.

The first one is that regarding the patient him/herself. By deciding to treat a patient without a chance to recuperate or at least to improve his/her condition is against the ethical principles of medicine.

The second aspect of futile treatment is the impact on the fate of other patients. It is unjust to transfer a

hopelessly ill patient to a special unit like ICU, when the number of beds is restricted and when other patients could really benefit by being treated there. In a study performed in 2003 on patients admitted to an Israeli hospital and in need of a bed in an ICU [23], we found out that almost 50% of critically ill patients were treated in a "normal ward" because of lack of beds in the specific intensive care environment.

The futile treatment creates a financial burden on any medical institution, since there is not a single hospital with an unlimited budget and unrestricted capabilities to treat critically ill patients.

Futile treatment produces moral distress amongst the staff members, especially the younger ones. Dzeng et al. [7] described the moral toll exacted upon the medical staff. Solomon et al. [24] called the use of futile treatment an act against the physician's conscience in providing care to the terminally ill. In their study the vast majority of the responders to a survey declared to be disturbed by the degree to which technological solutions influence care during the final days of a terminal illness.

Finally, the progress of medicine in the latter decades has created unjustified expectations among patients and their families. This is why we often encounter disagreement between the prognosis established by the physician and the unrealistic demands of the family.

In his paper on the paradox of health, Barsky [25] wrote about the "progressive medicalization of daily life, which brought unrealistic expectations of cure that make untreatable infirmities and unavoidable ailments seem even worse".

The reality shows that today we live longer, but a good part of our life is spent in bad shape and chronic, irreversible disease.

Coping with this rather new situation is the obligation not only of the medical staff, but of every single human being. But above all the medical staff must behave in a way which does not leave themselves open to questions related to the ethical approach regarding the hopelessly ill. The physician has to act in a transparent manner, to explain everything he is doing and to keep in close contact with the patient's family.

It has to be emphasized the fact that local regulations and prescriptions regarding the attitude towards the hopelessly ill patient could be very different from country to country and from place to place, but the main concept, shortly presented here, that of the obligation to take into consideration both the patient's interests and the community needs is universal and well recognized worldwide.

Conflict of interest

Nothing to declare

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Tratamentul pacientului critic incurabil: să ne oprim sau să nu începem?

Rezumat

Acest articol abordează subiectul tratamentului inutil în cazul pacienţilor în stare extrem de gravă, fără speranţă de recuperare. Subiectul are faţete multiple care includ principiile etice de evitare a tratamentului inutil, dar şi impactul economic şi logistic al tratării pacienţilor care nu au şanse reale de a beneficia de rezultatul aplicării tratamentului.

Articolul prezintă cazul unui pacient în vârstă de 75 de ani aflat într-un stadiu avansat de boală Alzheimer, cu tabloul clinic de abdomen acut chirurgical, şi discută două alternative de abordare terapeutică ale acestui caz.

Primul scenariu se referă la tratamentul intensiv al acestui pacient, incluzând laparotomia de urgenţă şi internarea în terapie intensivă, scenariu care nu prezintă şanse reale de a salva viaţa pacientului. Cel mai favorabil rezultat în acest caz ar putea fi reprezentat de întoarcerea pacientului la starea sa mentală anterioară, fără a fi conectat la realitate şi mediul înconjurător, şi cu o permanentă nevoie de asistenţă şi supraveghere.

Cea de a doua opţiune este reprezentată de alegerea de a lăsa pacientul să se stingă cu demnitate, fără dureri şi înconjurat de familie.

Este luat în discuţie rolul medicului de familie şi al familiei, sunt prezentate de asemenea câteva principii etice, cu scopul de a accentua importanţa eludării tratamentului inutil în cazul pacientului terminal.

Cuvinte cheie: bolnav incurabil, boală Alzheimer, etică, tratament inutil