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Point of view

End of life and palliative care in intensive care

Terminalidade e cuidados paliativos em terapia intensiva[☆]

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The history of mankind has been marked by different approaches regarding the acknowledgement of severe illness, the process of death and dying. The way to deal with these realities may differ widely within the spectrum of different cultures, but also at different times within the same social group. From the past, reports on the western civilization's habits show us that the rule was that severely ill individuals would stay in their homes, surrounded by their families until the time of the final outcome.

It is what it is described, for instance, by psychiatrist Elizabeth Kübler-Ross, one of the most important researchers of the process of death and terminal illness, in her autobiography entitled 'The wheel of life'. She tells us about how she was able to experience the moment of death of a close family friend who, after a severe accident, was considered a hopeless case by physicians: "At the hospital, doctors told him they could do nothing and, therefore, he insisted to be taken away to die at home. There was more than enough time for the family, relatives and friends to say goodbye to him. On the day we visited him, he was surrounded by his family and his children. His room was full of wild flowers and the bed had been placed in a position that allowed him to see through the window their fields and fruit trees, literally the fruit of his work that would survive over the years. The dignity, love and peace that I saw left an ever-lasting impression on me."¹

The development of medical knowledge, the increase in the number of hospitals and the introduction of technological innovations have brought several benefits to the treatment of different diseases, as well as the possibility to postpone the moment of death, with the use of artificial resources, for an almost unlimited period of time. Regarding the treatment of critically-ill patients, such advances have resulted in real hopes of survival in many cases.²⁻⁴

However, it has become quite common for the artificial support of vital functions to be extended indefinitely at any cost and, especially, with substantial loss of human dignity and quality of life. Many patients unable to achieve recovery find themselves in their moments surrounded only by machines, probes, catheters and unknown people, who sometimes may not be able to provide a humanized approach.

More recently, we began to realize that this practice constitutes an undesirable deviation of medical care. In a number of cases, medical resources are used in order to prolong life in situations with no chance of recovery, without significant benefits to the prognosis and quality of life, which is named disthanasia. It seems simple to admit that futile treatments in a final and irreversible phase of the disease are inhumane and unequivocally hurts human dignity. This is not, however, a rare practice today.

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Dysthanasia has as its counterpart, the orthothanasia, i.e., the use of therapeutic modalities to provide conditions for a peaceful and dignified death.⁵ Orthothanasia differs from and should not be confused with *euthanasia*, which means shortening the patient's life when there is still possibility of recovery or stabilization of their health – which is, incidentally, a crime in the eyes of the law.⁶ The physician must not intend – when practicing orthothanasia – to accelerate death, but rather to provide means for patient comfort above all. Undoubtedly, it is necessary to take into account the disease severity, the impossibility of cure, patient rehabilitation and the depletion of therapeutic possibilities on which benefits have been demonstrated.⁵

The analysis of the possible causes for the persistence of dysthanasia as common practice, a true dystocia in medical care, is not very simple. The problem seems to have its roots in the cultural, moral and ethical values adopted by society, but in a very peculiar way, on medical education models followed by our educational institutions. In general, medical education has been based exclusively on a biotechnological approach, aiming primarily to reverse the pathological processes, but without giving significant attention to the human aspects of the disease and the patient.

Therefore, there seems to be an antidote for everything. The arsenal ranges from last-generation antibiotics, advanced dialysis systems, complex mechanical ventilators and even artificial circulatory support systems, prioritizing the maintenance of life at all costs. Little or nothing is learned during the academic life and even after, during the exercise of the medical profession, about alleviating suffering, or how to keep intact the limits of human dignity.⁵

It should be emphasized once again that this is not about denying treatment to critically-ill patients, but rather the promotion of human dignity through more appropriate and less invasive therapeutic modalities. With these principles in mind, it becomes necessary at this point for health professionals in all areas of care to take an active and positive stance, discussing and suggesting changes in all ICUs in our country.

While it is convenient for some to wait patiently for death, which comforts the soul and creates the illusion that “everything is being done and offered,” the attitude to be stimulated is to approach the patient first, the focus of our attention, whenever possible, as well as their families, about the real life expectancy at that time, clearly and honestly. Then, one need to suggest the non-institution of aggressive treatment and even the suspension of these when it becomes evident to the team that the line of hope has been crossed in terms of treatment and the possibility of any reversal of the disease.⁷⁻⁹ We should not have the right to change the inexorable course of death of the terminally ill into a model of experimental death, never taught in academic classes.

In many cases, it is possible to suppress, incrementally and progressively, the use of therapeutic interventions recognized as futile, offering a peaceful death without the suffering caused by repeated interventions. Objectively, one should consider stopping hemodialysis, vasoactive drugs, antibiotics and even mechanical ventilatory support. In contrast, there is a vast arsenal of drugs such as sedatives, analgesics and a

whole range of resources to reduce symptoms such as anxiety, dyspnea, agitation, delirium, which can be used widely and through different administration routes, always aiming at offering comfort and dignity. Imaging studies performed near the time of death can be avoided, as they do not add to the well-being of the patient. Such measures should lead to reversal of a harsh reality: that of the human being that has been “forgotten” at the ICU, when the patient once again becomes the center of attention of family members and health professionals, similarly to that reported in the above example, a death scene from the beginning of the last century.

Another aspect to be considered is related to the adequate management of intensive care resources.^{2,10} Currently, there are about 25,000 ICU beds available throughout the country.¹¹ Many patients whose disease is at an advanced stage, irreversible, incurable and with the prospect of imminent death, are admitted to these units and receive daily treatments with the most advanced technological devices available.

Scarce financial, human and biotechnological resources allocated to this sector are thus wasted with these patients who truly require analgesia, comfort and the presence of family members, wasting the chances of many others with a real chance of recovery. If we estimate that roughly 20% of these beds are occupied by patients who require palliative treatment, it means that at least 5,000 beds/day or 150,000 beds/month are not available for patients with reversible disease, which means increased costs of health with irreparable loss to society.

Although certain attitudes directed at the well-being of the patient and against the imposition of futile treatments have already been established in some Brazilian hospitals (and widely disseminated and applied in different European and U.S. institutions for over two decades), following the resolutions of the Medical Councils, some perplexity and resistance are still observed on the part of health professionals.

Notably, from the ethical-professional point of view, we can say that the obstinacy or unlimited therapeutic compulsion are in disagreement with Resolution 1.805/2006 of the Federal Council of Medicine (CFM) and the Code of Medical Ethics/2009, according to which it becomes the right of patients and their families to chose the cessation of therapeutic measures for the benefit of comfort and well-being of the patient, once the situation of terminal illness has been confirmed.^{5,9,12} In addition, in line with the recent resolution of CFM, it is given to the patients the right, through living wills and advance directives, to have their resolutions followed regarding the care to be provided in the moments before their death.¹³

In conclusion, it is important to admit, at this stage of technological medical development and considering all therapeutic resources available, that the greatest antidote to the physical and spiritual suffering of the terminally-ill patient is human comfort together with their families and loved ones. Otherwise, we will not be providing a doctor's primary function, which is to offer relief to suffering, especially in the final moments of life. The last breath of our lives should be reserved for the eternal embrace of the most beloved person in our lives, and not the coldest technology.

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