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Life and death in the ICU: ethics on the razor's edge

Leo Pessini

Abstract

This article seeks to address some ethical issues experienced on the borders of life and death in Intensive Care Units (ICUs). These are special places in hospitals, where there is the mandatory presence of cutting-edge medical technology and support for the preservation of life of a patient in a critical condition or risk. It is in this complex context that difficult ethical issues emerge: there are no objective criteria for admissions to the ICU, ICUs can be overcrowded with patients without diagnosis and there are difficulties in limiting treatment, which results in medical procedures that only prolong the dying process of the patient. We analyzed a case of assisted suicide, the young American Brittany Maynard, the need for Palliative Care, the ethical duty to care for pain and human suffering, the need to rediscover the paradigm of care, in search of an end to life without pain and suffering, and to avoid the practice of "medical futility", which only prolongs the dying process and only imposes more suffering on the patient, family members and health care professionals.

Keywords: Palliative care-Pain management. Euthanasia-Hospice care. Medical futility. Bioethics-Intensive care units.

Resumo

Vida e morte na UTI: a ética no fio da navalha

Este artigo busca abordar algumas questões éticas vivenciadas nas fronteiras de vida e morte, nas unidades de terapia intensiva (UTI). Esses são locais especiais no âmbito hospitalar onde é obrigatória a presença de tecnologia médica de última geração, para preservar e sustentar a vida de pacientes em estado grave ou em risco. É nesse contexto complexo que emergem difíceis questões éticas: ausência critérios objetivos para internações em UTI; superlotação das UTI, com pacientes sem indicação; até as dificuldades de limitar a terapêutica, que se transforma em práticas distanásicas. Analisamos um caso de suicídio assistido, da jovem estadunidense Brittany Maynard, bem como a necessidade de cuidados paliativos, o dever ético de cuidar da dor e sofrimento humanos, a valorização do paradigma do cuidar para além do curar e a polêmica questão da ortotanásia, em busca de um final de vida sem dor ou sofrimento, mas em paz e com dignidade.

Palavras-chave: Cuidados paliativos-Manejo da dor. Eutanásia-Cuidados paliativos na terminalidade da vida. Futilidade médica. Bioética-Unidades de terapia intensiva.

Resumen

La vida y la muerte en la UCI: la ética en el filo de la navaja

Este artículo intenta abordar algunas cuestiones éticas vivenciadas en las fronteras entre la vida y la muerte en las Unidades de Cuidados Intensivos (UCI). Estos son lugares especiales en los hospitales, donde existe una presencia obligatoria de tecnología médica de vanguardia, para preservar y mantener la vida de un paciente en estado grave o en riesgo. Es en este contexto complejo que surgen cuestiones éticas difíciles: ausencia de criterios objetivos para la admisión en la UCI; condiciones de hacinamiento de pacientes sin indicación; dificultades para limitar los tratamientos que se convierten en prácticas distanásicas. Se analizaron: un caso de suicidio asistido, de la joven estadounidense Brittany Maynard; la necesidad de cuidados paliativos; el deber ético de cuidar del dolor y del sufrimiento humano; la recuperación del paradigma de la atención más allá de la cura y la controvertida cuestión de la ortotanásia, que apunta al fin de la vida sin dolor ni sufrimiento, pero en paz y con dignidad.

Palabras-clave: Cuidados paliativos-Manejo del dolor. Eutanasia-Cuidados paliativos na terminalidade de la vida. Inutilidad médica. Bioética-Unidades de cuidados intensivos.

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Declara não haver conflito de interesse.

*I am immediately transported to the ICU. And then, I had an experience that was, to say the least, unusual. In ICU life is on hold. Time stands still – in fact, there are no clocks on the walls. The light never goes off: it is not day; it is not night; a flat, unchangeable, glare reigns. But movement is continuous; doctors, nurses, nurse assistants circulate non-stop, examining and manipulating patients, who are always in a serious condition.*¹

In *ICU life is on hold*, Moacyr Scliar, a doctor and famous writer from the south of Brazil, defines in the epigraph that frames the introduction of our ethical reflection on the use of ICUs, after his experience of spending some time in one of them, while recovering from a health problem. In this poetic image, Scliar, as a respected author and medical professional with knowledge of medical matters, captures the popular imagery well in relation to the contemporary medical therapy specialty of “saving lives.” There, life is like being in “limbo”, as if one has exceeded the “dangers of being mortal” and the threshold of death, being in a new state, “on hold”.

ICUs are now hospitals units that care for human life in critical situations that present great complexity and drama. On the one hand, we are facing magnificent expressions of technical and scientific progress of medicine, which performs real “miracles” by saving lives that, until very recently, would have been simply impossible to save, except in dreams! On the other hand, the fact that we may be required to undergo a prolonged, painful and useless process of death is disturbing and scary!

This is the heart of the problem called “therapeutic obstinacy”, or medically futile and useless medicine, or simply “dysthanasia”, which can transform the end of our lives, making us mere prisoners of technical apparatus that, more than prolonging life at the end of human life, transforms these moments into really torturous pain and suffering. In this context of intensive and critical care, feelings of hope waiting for a “miraculous” recovery, which would be difficult but possible, added to the fear and deep anguish of losing your own life or the life of someone dear, are incredibly similar!

It is also important to define, at the outset, what constitutes an Intensive Care Unit (ICU). The Conselho Regional de Medicina do Estado de São Paulo (CREMESP - Regional Council of Medicine for the State of São Paulo), through Resolution 71/1995, defines ICU, in its Article 1, as *the location within a hospital that has the objective of caring for, under a continuous monitoring system, critically ill*

*or high-risk patients, who can potentially recover*². Article 2 of the same Resolution specifies the “critically ill patient” as one that *presents instability in one of their organic systems due to acute or chronic changes and the “high-risk patient” as one who has a condition that can be determined as potentially unstable.*

The Brazilian Ministry of Health, through the Agência Nacional de Vigilância Sanitária (ANVISA - National Health Surveillance Agency), stipulates the minimum requirements for operating an ICU operation, defining the *critically ill patient* as one who *presents impairment of one or more of the major physiological systems, with loss of their self-regulation, needing continuous assistance*³. ANVISA also defines ICU as *a critical area for the hospitalization of critically ill patients who continuously require specialized professional attention, as well as specific materials and technologies necessary for diagnosis, monitoring and therapy.* The document classifies the ICUs into several categories:

- a) Adult ICU: *for the care of patients aged 18 or over, and may admit patients of 15-17 years, if that is specified in the rules of the institution.*
- b) Specialized ICU: *for the care of patients selected by type of disease or intervention, such as cardiac, neurological, surgical, among others.*
- c) Neonatal ICU: *for the care of admitted patients aged between 0 and 28 days.*
- d) Paediatric ICU: *for the care of patients aged 29 days to 14 or 18 years, a limit defined according to the routines of the institution.*
- e) Mixed Paediatric ICU: *for the care of new-borns and paediatric patients in the same room, although there is a physical separation between the Paediatric ICU and Neonatal ICU environments*³.

The ethical issues that present themselves today in ICUs are numerous and complex: therapeutic decisions to invest or not in the treatment of a patient; definitions as to whether a state is reversible or not; administration of nutrition and hydration; communication of bad news; family participation in the decision process related to the patient; professional interaction of the care team working in the ICU with patients and their families (humanization); judicial decisions for admission of patients in ICU, among many others. Each one of these topics can be discussed in depth in a separate chapter, which we have done in various other works of public knowledge⁴⁻⁸, although in this text we will focus only on the question of *the dignity of life and death*

in the ICU, to highlight the point we aim to discuss in depth.

Despite medical advances in critical care or scientific medicine, the ICU still remains as the unit where many patients die. Among patients with chronic diseases who die in the hospital, approximately half are cared for in the ICU in the three days before their death and a third pass at least 10 days in the ICU during the final period of their hospitalisation. In 1995, approximately 20% of all deaths in the United States (US) happened in an ICU. Studies in the US, Canada and Europe have shown that most deaths in ICUs involves difficult decisions regarding the use of life-sustaining treatments for critically ill patients who no longer respond to critical care therapies. An important goal is to provide a death without pain and suffering for these patients and a compassionate care to their families⁹.

*Death never ceases to be current and provoke us in terms of life. It always has an unplanned meeting with us, visiting us in a silent, gentle and surprising way, forcing us to reflect on our own finite life through the loss of loved ones, or, through unusual and unexpected situations that frighten us*¹⁰.

The question is so disturbing and poignant that art, literature and media, frequently discuss it. Among the films that address this theme, the Oscar-winners stand out "The Sea Inside"¹¹ and "Million Dollar Baby"¹², which present euthanasia as a solution in face of a life marred by suffering and dependence. In the social sphere, the first public policies also begin to emerge. An example of this is the legalization of euthanasia in 2002 in the Netherlands and Belgium¹³. In the latter, *the extension of the practice of euthanasia for minors* was approved in 2014, reigniting *the international debate on medical decisions concerning the end of life in children*¹⁴.

In March and April 2005, the case of Terri Schiavo expanded beyond the limits of American discussions and reached the international public forum. After 16 years in a persistent vegetative state, Terri died of starvation, at the age of 43, on the 31st March 2005, 14 days after the removal of the feeding tube¹⁰. Almost concurrently, on the 2nd April, Pope John Paul II said farewell to mankind after exposing his excruciating agony and suffering, which has drawn criticism and caused discomfort for many. In the end, wisely, the Pope refuses to return to the hospital, choosing to spend his final moments in his own chambers¹⁵.

While these isolated events caused worldwide commotion, several wars, rebellions and conflicts

killed thousands of people around the world: Kashmir, Darfur, Colombia, Afghanistan, Somalia and Uganda are some of the countries where armed conflicts have lasted decades. The 2005 news reporting on dozens of deaths in daily attacks in Iraq, where the war continues to this day, did not cause the same stir in the media: the dead were people "without face or name," simply identified as "civilians" or "soldiers". The contrasts and contradictions of the situation are exemplified with the position made public by then US President George W. Bush who, at the time, declared himself a champion of the "culture of life" when positioning himself regarding the Terri Schiavo case, although he was the protagonist and promoter of the war in Iraq¹⁶.

At the end of 2014, the world witnessed another American case that had a great impact, which happened in the state of Oregon, where the practice of assisted suicide is legally allowed¹⁷. It refers to young Britney Maynard, who, in January 2014, found out she was suffering from a fatal disease that condemned her to have only a few months of life left. Fearing for an excruciating and painful death, Britney decided, in accordance with her young husband, her family and her doctor, to go through an assisted suicide, which was carried out on the 2nd November of the same year¹⁸. At this historic moment, the Supreme Court of Canada legalised assisted suicide in that country, and France legalised deep sedation, a treatment that has been criticized as a form of "disguised euthanasia"^{19,20}.

Palliative care: an emerging and urgent need in the health system

In 2002, the World Health Organization (WHO) defined "palliative care" (PC), emphasizing the elimination or reduction of pain and suffering: *Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual*²¹.

From this definition, one can think of a philosophy that specifies some fundamental principles of palliative care: a) appreciating the achievement and maintenance of an optimal level of pain and the management of symptoms; b) affirming life and regarding death as a normal process; c) not hastening or postponing death; d) integrating psychological

and spiritual aspects of patient care; e) offering a support system to help patients live as actively as possible until the time of their death; f) helping families to face the patient's disease and mourning; g) considering the family a care unit, together with the patient; h) requiring an inter and multidisciplinary approach (teamwork); i) aiming at improving the quality of life; j) being applicable to the initial stage of the disease, concurrently with the changes of the disease and therapies that prolong life.

Another ethical and human aspect that has a great impact on relationships and human and professional interactions, which has just been mentioned before, is considering the patient and family as a unit of care. Assistance to families is one of the most important aspects of the overall care of ICU patients, and one of the pillars of humanised care.

The care provided to the family still deserves the necessary respect, both regarding caring and regarding the training process of professionals. The family's desire to stay close to the patient and also to be adequately informed of the progress of the patient's health status is understood as a human need. Prolific contemporary literature shows that care strategies focusing on family members (encompassing not only blood relatives and spouses, but also all those who are part of the patient's close circle) result in greater satisfaction and better perception of the quality of the care provided to ICU patients. Improvement in communication, prevention of conflicts related to values and choices, and spiritual support, are some of these strategies, to name a few^{7,22}.

Despite the existence of these studies, the production of new works on this topic is very welcome, as it is important to continue to deepen the studies on ICU visitation policies, seeking to reconcile the procedures and routines with a greater flexibility regarding the presence of family members. From the tolerated "special visits" in cases of end of life, which are aimed almost only at saying last farewells to loved ones, we shift to the effective participation throughout the whole care and support process. Patient and family must be at the centre of the attention and care^{23,24}.

In terminal situations, patients' family members have specific needs that must be taken into account. These requirements are summarized in the recommendations of the Society of Critical Care Medicine, located in the State of Illinois (USA), in the following terms: be close to the patient; feel useful to the patient; be aware of changes in the clinical condition - effective communication; understand

what is being done in the treatment and why; have safeguards regarding the management and treatment of pain and suffering; be sure that the decision on the curative treatment limitation (interrupting or suspending some therapy, medication or procedure) is appropriate; be able to express their feelings and anxieties; be comforted and consoled; and, finally, find a meaning for the patient's death^{25,26}.

Treatment of pain and suffering as a fundamental right

Pain and suffering are companions of humankind since time immemorial. Today, pain control and relief constitute fundamental skills and ethical responsibilities of health professionals. This action is a key indicator of quality of the pain and suffering treatment, as well as of the patient's holistic health care.

Pain is a symptom and one of the most frequent causes of demand for health services. In many health institutions that are now at the forefront of holistic care of human beings that have been made vulnerable by some serious illness, and, therefore were forced to face excruciating pain. This pain experience is recognized as the fifth vital sign integrated into clinical practice. If pain were treated with the same zeal that other vital signs (temperature, blood pressure, breathing and heart rate), there would be, without doubt, much less suffering. The purpose of assessing pain is to identify its cause and understand the sensory, emotional, behavioural and cognitive experience it represents for the person, with a view to promoting its relief and care.

Today it is recognized that pain is a disease. According to the WHO definition, health is *a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity*²⁷. It is clear that the painful conditions constitute a state of infirmity; therefore, a human being suffering from pain is not healthy, and it can be said - legitimately - that there is a violation of their inalienable right to health. Article 25 of the *Universal Declaration of Human Rights* recognizes as one of the rights of human beings *a standard of living adequate for the health and well-being*²⁸. Unfortunately, health and well-being are not always a possible choice, as in many situations, many people, because of old age or disease, feel pain and suffer a great deal at the end of life.

The difference between pain and suffering has great significance, especially when dealing with

terminal patients. Dealing with pain requires the use of analgesic medication, while suffering calls for compassion to strengthen the spirit and the notions of significance and meaning of life, because unexplained pain often turns into suffering. And suffering is a deeply complex human experience, which involves the identity and subjectivity of the person, as well as their socio-cultural and religious values.

One of the main dangers in neglecting the distinction between *pain* and *suffering* is the tendency of treatments to focus only on symptoms and physical pain, as if these were the only source of anguish and suffering for the patient. There is a tendency to reduce suffering into a simple physical phenomenon, which can be more easily identified, controlled and dominated through technical means.

Moreover, this relationship enables us to continue aggressively with futile treatment, believing that if treatment protects patients from physical pain, it will also protect them from all other aspects, including their existential angst. The continuity of such "care" can impose more suffering on terminal patients and their families¹⁰. Suffering has to be seen and cared for in four key dimensions²⁹, explained below.

Physical dimension

At a physical level, pain works as clear marker, warning that something is not functioning normally in the body.

Psychological dimension

It emerges into consciousness when one must face the inevitability of death; when dreams and hopes vanish and there is an urgent need to redefine the world that one is about to leave.

Social dimension

It is the pain of isolation that arises when the person who is dying realizes that they will no longer live, but the world as they know will continue to exist. It is the suffering of feeling inexorably touched by a destiny one does not want to experience, and the loneliness for knowing that it is impossible to fully share this reality that requires redefining relationships and communication needs;

Spiritual dimension

It arises from the loss of meaning, purpose of life and hope. Everyone needs a horizon of meaning – a reason to live and a reason to die. Recent

research in the US shows that^{30,31} advice on spiritual matters is among the three needs most requested by terminally ill patients and their families. The CFM (Brazilian Federal Council of Medicine), took a stance that was recently approved in a plenary consultation regarding "*religious/spiritual assistance to patients in ICU*" and reported by Councillor Henrique Batista e Silva, concludes that *scientific studies show that the provision of religious spiritual assistance can bring benefits to the health and well-being of ICU patients. Moreover, as this provision is supported by national legislation and ethical devices, the hospital has the duty to facilitate and ensure this assistance when demanded by patients and/or their family members, as long as the current rules of the hospital and the clinical condition of the patient are respected*³².

The George Washington University School of Medicine and Health Sciences, based in Washington (USA), in line with the Association of American Medical Colleges, defines spirituality as *a factor that contributes to health in many persons. The concept of spirituality is found in all cultures and societies. It is expressed in an individual's search for ultimate meaning through participation in religion and/or belief in God, family, naturalism, rationalism, humanism, and the arts. All of these factors can influence how patients and health care professionals perceive health and illness and how they interact with one another*³³.

Healing and caring paradigms

Health actions are now increasingly marked by the healing paradigm, characterized by critical and intensive care in high-tech medicine. The massive presence of technology is indeed a necessary and legitimate fact in contemporary medicine. But the healing paradigm can easily become a prisoner of technology because, when facing the pulse of life, it is not hard to forget that medicine is a means, not an end.

The healing paradigm induces the adoption of an ethic of uncritical problem solving - if something can be done, then, it should be done - and to forget that not everything that is scientifically possible to perform is ethically permissible. It also calls on the idolisation of physical life and feeds the desire to prolong life, even when the quality of life deteriorates and living is restricted to truthfully unacceptable conditions. *This vitalism takes shape in the belief that the inability to cure or to prevent death is a*

*failure of medicine*¹⁰. The failure of this logic is the fact that the responsibility of healing ends when all possible treatments are exhausted, and when there are no further healing options, one should admit, "there is nothing else to be done."

Opposing this emphasis on healing, another line of interpretation and understanding begins to gain strength among scholars and health professionals: *the caring paradigm*. Based on understanding and caring for terminally ill patients and their families, this new concept has attracted growing public interest, motivating discussions on euthanasia and assisted suicide. This perspective draws attention to the limits of "healing" imposed by medicine: *Under the caring paradigm, health care accepts decay, aging and death as part of the human condition, all of us "suffer" from a condition to which there is no cure, that is, we are mortal*¹⁰.

The process of determining the reversibility or not of a clinical condition is critical in the ICU, as Doctor Vitor Oliveira stated:

*The judgment of the technical inevitability of death is one of the most sensitive procedures among those that can be made in an ICU, as it is an opinion that has a high impact on a human life, on a person who has a long and rich history, who has dreams and desires, who loves other people and who has family and friends that love them back. It is imperative to admit that this is the life of a person who, unless they clearly expressed otherwise, wants to continue living and counts on our professional work for it. Because it is this way, both so delicate and with universal, ethical and moral impact, that the judgment of the technical inevitability of death and also its previous corresponding dilemma, the technical inevitability of clinical worsening of the patient, which is so necessary in an ICU, that the judgement must be submitted to broad and critical scrutiny, in the search for errors, before being minimally accepted. (...) There will be nothing more valuable to a human life in ICU and to their family members than discovering errors in our judgment regarding the impossibility of treatment and of saving that life*³⁴.

Unfortunately, today ICUs have, in practice, turned into spaces for the technical management of life and death. However, the challenging ethical perspective is to recover its original role, that is, their reason for being, which is to apply all the medical science known to promote the improvement of the health of the person hospitalized. In our community, care and palliative actions in the intensive care unit is also advocated³⁵.

The truth is that medicine cannot stave off death indefinitely. Death finally ends up arriving and winning. The key question is not whether we will die, but when and how we will have to face this reality. When medical therapy cannot achieve the goals of preserving health or alleviating suffering, treating to cure becomes a futility or burden and, rather than prolonging life, extends the agony. What follows is the ethical imperative to stop what is useless and futile, stepping up efforts to provide quality, rather than quantity, of life in the face of death³⁶.

About the controversy over orthothanasia in Brazil

Starting from the perspective that death is a dimension of our human existence, as we are finite and mortal, and have the right to live with dignity, and the right to die with dignity, without suffering or artificial prolonging of the dying process (dysthanasia) is implicit. However, this does not give us the right to shorten life, which would be the practice of euthanasia. Resolution 1805/2006 of the Brazilian Federal Council of Medicine goes against dysthanasia and euthanasia, being favourable to orthothanasia, that is, dying naturally without pain and suffering, when life is neither abbreviated nor prolonged in its final phase:

Art. 1^o *The doctor is allowed to limit or suspend medical procedures and treatments that prolong the life of terminally ill, critically ill and incurable patients, respecting the will of the patient or of their legal representative.*

Art. 2^o *The patient will continue to receive all the care necessary to relieve the symptoms that lead to suffering, ensuring holistic care, physical, mental, social and spiritual comfort, inclusive ensuring them the right to discharge.*³⁷

The judiciary, in this case the judge who embargoed the resolution in Brasilia, needs more ethical and bioethics culture to distinguish the concepts of euthanasia and orthothanasia because one can clearly see that the arguments presented have been shuffled. The understanding of orthothanasia is that if the person is dying, we will not shorten their life by practicing euthanasia in their last moments, much less prolong their agonizing process, which would be a futile practice that should also be avoided. The process to cancel the Resolution 1805/2006 ended in December 2010, with a favourable decision for CFM. The resolution is in full force.

This resolution is a breakthrough for Brazilian medicine in the sense of preserving the dignity of the human being at this critical time of life, going beyond mere “biologism”. Human life, beyond its physical-bioethical dimensions is, in a special way, also a “biography”. We must begin to discuss and talk about “health and biographical dignity.” We need to use technology wisely, saying a big no to “technocracy” and recognize that all human lives come to an end, and that this end should be culminated with respect and dignity.

Here we need ethical wisdom to realize that, in certain situations, we are facing a human being whose life is coming to an end, and ignoring this reality would simply be a disaster. Why? We end up treating death as a disease for which we need to find a cure, but we are not dying patients. The dimension of mortality must be taken into account. No matter how much technology advances, and we hope it continues to advance, it will not give us the gift of biological immortality.

It is important to remember what Dr. Reinaldo Ayer, member of the Conselho Regional de Medicina do Estado de São Paulo (CREMESP - Regional Council of Medicine for the State of São Paulo) and professor at the Faculty of Medicine of the University of São Paulo, said to “Gazeta Digital” in 2006:

the ICU is a place with a concentration of specialised equipment and people with the objective of caring for patients that present an acute worsening of their condition with therapies available to help them. However, today about 30% of patients who are taken to an ICU have no expectation of improvement, which means that there is no more treatment for them. This does not mean that these patients should be abandoned. They should stay in a room or in a semi-intensive unit, receiving palliative care close to their families³⁸. These patients should not be in the ICU, but getting so called palliative medicine because, when a cure is no longer possible, we should invest in comfort, caring for the physical, psychological, social and spiritual needs. On top of unnecessarily investing expensive resources on these cases, we end up imposing more suffering on patients and families members. How about spending less, investing wisely where it really is necessary, that is, where there is really hope of healing? How about having the courage to recognize that, in certain situations, we reach a limit that must be respected and that the best we can do in such situations is to provide more comfort so that the person does not feel pain or suffer unnecessarily? This truth

is what the health system and health professionals need to understand.

Fortunately, in Brazil, the last Code of Medical Ethics (CEM), in force since 2009, admitted among its fundamental principles the principle of human mortality (item XXII): *In irreversible clinical situations of terminal patients, doctors will avoid performing unnecessary diagnostic and therapeutic procedures and will provide patients under their care all appropriate palliative care*³⁹. Finally, Brazilian medicine definitively entered into the twenty-first century, by explicitly admitting to the reality of death in medical practice, and by limiting therapeutic investments that would have as a consequence the practice of futility, dysthanasia.

In this sense, it is important to remember Pope John Paul II who, realizing that his life was coming to an end, said no to the proposal to return to the Gemelli Hospital in Rome. He refused to do so and simply begged: *“Let me go to the house of the Father”*¹³. Going back to the hospital, staying in an ICU, his biological physical life could certainly have been extended for several days; but how would that be of benefit to him? And it is interesting that no one says that the Pope opted for euthanasia; what was avoided was the practice of dysthanasia. The Pope’s request when saying *“let me go”* is still the cry of hundreds of thousands of patients who today are in the final stage of life.

Final considerations

In good conscience, we cannot passively accept death when it is a result of a disregard for life, caused by violence, accidents and poverty, and in the face of which we must cultivate an ethical and righteous indignation¹⁰. However, in contrast, we must tangibly re-evaluate therapeutic actions and the manner in which medical purposes are being put in practice, as well as establish clear guidelines for the use of ICU in our hospitals and health care system. It is clear that medical schools usually teach young students only to save lives, but not how to deal with death. From this perspective, death will always be seen as an enemy to be fought and feared. In this professional view, the duty of a “competent” physician is to utilize the full therapeutic armoury available to prevent the end. It does not cease to be part of the truth of “humanized” medicine.

Yes, saving lives, helping to regain health whenever possible, is, without a doubt, one of the most important purposes of medicine. The other

side of the coin, as important as this primary purpose of alleviating human suffering and healing whenever possible, is to help people to say goodbye to life with dignity. The finite dimension of humanity cannot be seen as a condition to be cured. Death is not a disease; it is a dimension of our human condition. Recognizing and respecting limits is an ethical imperative of the first order in this specialized area of medicine that covers intensive and critical care.

Ahead of us lies the huge educational challenge of reminding health professionals in general, particularly physicians, and the public, of the original understanding of what is an ICU: basically a special unit of critical care in which patients who have the possibility of cure (potential to return to their state of health) are hospitalized.

Today, the scenario is still very complex and complicated in this sense, that we know that, at least in Brazil, only 30% of patients who are in Brazilian ICUs are terminal... As mentioned before, these patients should be receiving care for their physical, psychological, social and spiritual comfort. A myth has been created that portrays ICUs as a place where miracles occur... Yes, indeed, but we can easily incur futile procedures, that is, the undue protraction of the dying process. Ethics in ICU sails on the "razor's edge": any wrongdoing inevitably leads to disastrous consequences. In this context of care, scientific daring has, necessarily, to go hand in hand with ethical prudence:

The ethical challenge is to consider the question regarding the dignity of dying, beyond the physical and biological dimension and beyond the medical-hospital setting, expanding the horizon and integrating a socio-relational dimension. There is much to be done to bring society to understand that dying with dignity is a result of living with dignity and not merely surviving. If there are no conditions for a decent life, at the end of the process would we ensure a dignified death? Before the right to a humane death existed, it was necessary to emphasize the right of the already existing life to have these conditions maintained and preserved, so that it could fully flourish. We would call this the right to health. It is shocking and ironic

to see situations in which the same society that denied human beings bread to live now offer them the latest technology to "die well"!¹⁰

We are all sick or "victims" of death, as it is healthy to be pilgrims in existence. Although sometimes we may be cured of diseases remain classified as mortals, we cannot be indefinitely elevated beyond our mortality. When we forget this, we ended up falling into technocracy and into the pure and simple absolutism of biological life. Projecting our fear of finitude in health practices, we unwisely seek to "cure" death without knowing what to do with those who approach their farewell to life. It is therapeutic obstinacy (dysthanasia) to try and delay the inevitable, adding only more suffering and quantitative life, rather than quality of life³.

It is true that today we talk about the use of the ICU in relation to the possibility of recovering the health of critically ill patients. But we also cannot deny that today the vast majority of deaths in Brazilian hospitals occur in the ICUs. The more advanced the cultural perception of ever increasing technological care, the more frequent and distressing will be these questions regarding end of life choices, and the use, or not, of ICUs. This scenario will significantly increase the importance and need to promote an ethical and bioethical culture among health professionals, especially among intensivists who will have to deal with the challenge of managing increasingly conflictive situations in a context with a plurality of values, in which the decisive distinctions and ethical concepts related with the end of life will be the starting point of any discussion or ethical dialogue⁴⁰.

It is not without reason that the work of Atul Gawande, "Being Mortal: Medicine and What Matters in the End" deals exactly with the issues related to the limits of the possibilities of therapeutic investments and meaning at the end of life. The author reminds us that people at the end of their lives *want to share memories, pass on wisdom and keepsakes, settle relationships, establish their legacies, make peace with God, and ensure that those who are left behind will be okay. They want to end their stories on their own terms*⁴¹.

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