

Suffering and pain in palliative care: ethical reflections

Otávio Marambaia dos Santos

Abstract

The technological advancements associated to medicine lead physicians to have as tireless goal to overcome illness and to extend life. However, for patients who do not present any healing possibility, one extends suffering and the dying process. Palliative care is aimed at these patients whose disease does not respond to treatment anymore, and it has as priority the improvement of their life quality, through relief of physical pain and psychological, social and spiritual suffering. In order to introduce this concept one debates the change of paradigms regarding health professionals formation, which represent a new view of life, death and medical assistance, superposing care to healing whenever this is not possible anymore. One seeks, in the terminal patients' final phase of life, to maintain their existence honorable and comfortable, up to the last moment, having as bases the multidisciplinary care and the respect for the patient's autonomy, integrity and dignity.

Key words: Palliative care. Pain. Death with dignity.



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All indicators show marked improvement of human longevity. Life expectancy of up to 40 years, at the beginning of the 20th century, today, in developed countries achieves something around 80 years. The improvement of living conditions, the formidable progress of medical science and with its new preventive and curative technologies and the accelerated development of drug and interventionist therapies have made dying almost *impossible*¹. However, we know, death is inexorable.

The idea of being able to delay death leads patients and health professionals into not understanding and accepting this reality, making more difficult to participate, understand and accomplish the several stages of the dying process. In spite of all progress and increased longevity, two factors, alone or in combination, serve to lead us to death: disease and time. Living more exposes us to the devastating action of time; leads to weakening and it facilitates the work of diseases. Noises, time and disease lead to faster death.

Living more and the new technologies have changed markedly the role of hospitals. In the Lusophone world, for example, the institution which further demonstrates that is the Holy Houses of Mercy ¹, creation of Queen Leonor in the Portuguese lands in the continent and overseas - in Brazil, Macau and Goa. The Queen, compassionated with the suffering of the poor who, as a popular Brazilian saying *are so poor that they have nowhere to die*, decided to create these hospitals at the end of the 15th century. Currently, these institutions follow the modern hospital model, although in Brazil they are still engaged in the care of the most needed.

At the time that these institutions emerged, a hospital was the place where one went to die. And they, essentially, reproduced the social bias of the context in which they were inserted: rich people died at home and poor people in asylums. The hospital represented social exclusion and prejudice, because poor patients should be separated, thus avoiding the spread of diseases, even if not communicable. In the interregnum between the foundation of these institutions and the current time, deep and radical changes have altered the role of these hospitals. Presently, all stages of life, from birth to death, are objects of practices developed at this kind of institution. Currently, one goes to hospitals to prevent, cure, change aesthetically, and even to achieve social status: one can see in it the whole society, represented in its most varied aspects, from the most beautiful to the most terrible.

In spite of changes in the role of hospitals, in Brazil the social bias still persists by the existence of luxury hospitals, like brands, attended by the rich, and the generally more modest facilities, sometimes in the same building, that mark the separation between the rich and the poor and to whom simpler and less equipped wards are allocated; to the first ones, the suites and private and sophisticated apartments.

Improvement in the efficiency of therapeutic means and continued search for mechanisms of healing and life support technology have placed patients, without conditions of success in their treatments, in a situation of limbo: without possibility of healing they have their dying process paralyzed or extended so exaggeratedly, generating situations of continuous suffering ². A genuine *tour de force* was created: on the one hand, medical professionals using heroic and often useless measures; on the other hand, patients depleted in their expectations and certainly painful and causing suffering to those who surround him.

In Brazil, at least two legal and ethical attempts have been proposed to establish limits to this situation of therapeutic obstinacy. In the State of São Paulo, the so-called *Covas Act*, sanctioned by Governor Mario Covas, himself victim of cancer and apparently already thinking in himself, prohibited through this legal document the insistence of die-hard treatment in patients without prospects of cure or on terminal condition ³.

The other document is the Federal Council of Medicine (CFM) Resolution No. 1,805/06 ⁴, which sets forth: *in the terminal stage of a serious and incurable disease, the physician is allowed to restrict or suspend medical procedures and treatments that will prolong the patient's life, ensuring him the necessary care to relieve symptoms that lead to suffering, with a view to full assistance, respected the patient or his legal representative's wishes.*

Object of legal contestation and debate, the resolution was brought to the courts, and recently had a favorable final decision by the justice, being fully into force. It is important and salutary to know the decision from the final sentence of Proceeding 2007.34.00.014809-3 of the Federal Court of Brazil (annexed hereto) ⁵. More recently, the new Code of Medical Ethics (CEM) sets forth in Article 41, single paragraph: *in cases of incurable and terminal disease, the physician should offer available all palliative care without useless therapeutic or diagnostic obstinacy actions, always taking into consideration the patient's express wish or, when he is unable to do so, his legal representative* ⁶.

The border is, then, drawn to prevent physicians' therapeutic obstinacy in terminal patients, blocking actions that in most times do not represent any possibility of reversal or healing of the disease, can produce more suffering for the patient and his loved ones. The introduction of the

concept of palliative care for patients whose possibility of cure or control of the disease cannot be envisaged entails not only legal changes, but paradigms in the formation of physicians and other health professionals ⁷. And not only these, but, mainly, in those, already active, who need to understand the new approaches and ethical stances for patients in this situation.

Seeking to stimulate a reflection essential to healthcare professionals and, specifically, the medical class, the origin and the concepts of palliative care will be approached, beyond the current stage of this theme in Brazil. The handling of suffering and under palliative care shall be the core objective of this article.

Palliative care: what's all about?

From changing of hospitals into structures around which human life transits, particularly in large cities, where, unlike the past, one seeks the cure and not death, it was created the almost mythical idea that these spaces are able to free humans from their inescapable fate. In an apparent paradox, nobody accepts and nobody dies anymore at home nowadays.

The very architecture of cities, with its high buildings, does not facilitate the eventual movement of the corpse of a dead person through its facilities. In parallel, care of a chronic patient demands time and availability which, by the *difficulties* of modern life, causes families to transfer

this caring to hospitals. One dies in hospitals, but it is expected that this will not occur, since these new *cathedrals* concentrate the technological arsenal and drugs needed to avoid it⁸.

A contribution to the consolidation of this myth is that, since the creation of intensive care units (ICU), physicians and other health care professionals' struggle won a physical space in which they focus so hardhearted in fighting the diseases. Overcoming the disease and preventing its lethal success is the regulatory framework of the health team. Such obstinacy leads to a disassociation between the patient (person) and the disease that afflicts him. In such a way that, when trying to treat the disease, one forgot to reflect on the person, the individual and unique being suffering with illness. In an effort to heal, caring is forgotten!

In order to modify these parameters and to promote a caring medicine and giving a dignifying support to patients in their inexorable course, incurable and/or terminal diseases, the vision of *hospice* was crystallized in several places in the world, whose more referenced and modeled example is the work initiated by MD Cicely Saunders at the Saint Christopher's Hospice, in London, in 1967.

The introduction of evidence based medicine helps to avoid futile treatments, setting performance rates that show the progressive multiple organ failure and validating or not therapeutic investments in

patients under such conditions and attached to the criteria proposed by Saunders⁹: quality care for the patient and his family; variety of services provided to the patient, whether at home or at the hospital; evidence-based actions; research and evaluation.

Palliative medicine, still according to Saunders⁹, must have as pillars the multidisciplinary care and respect to the patient's integrity and dignity, who must be maintained without pain as much as possible; receive continuous care (not being abandoned); and whenever feasible, informed of everything that occurs with his treatment, so he can decide on it; be respected as to his distress and fears, feelings, values, beliefs and hopes. Finally, if he is able and wishes, deciding where to die.

It is a mistake to imagine that palliative care is intended only to prepare the patient for death. In fact, the goal is to keep a dignifying and more comfortable existence of the patient until his death. Thus, it may be necessary, inclusively, interventions from several experts who, without the intention of curing, can provide comfort and restoration of functions, albeit transitional, or which enables the patient to undergo them without suffering or constraint. It should be emphasized that these interventions cannot be a cause for more pain, separation or isolation.

The World Health Organization (WHO)¹⁰ defined palliative care as the total active

care of patients whose illness no longer responds to treatment. Its priority is the relief of pain and other symptoms, as well as the problems of psychological, social and spiritual nature. The objective of palliative care, therefore, is to provide the best quality of life for patients and their families.

In 2002, WHO highlighted the early identification of suffering by defining palliative care as: *an approach that aims to improve the quality of life for patients facing problems arising from an incurable disease with limited prognosis and/or serious illness (life threatening) and their families, through the presence of a multidisciplinary team and relief of suffering, with recourse to early identification, proper evaluation and rigorous treatment of the symptoms not only physical, such as pain, but also the psychosomatic and spiritual ones*¹¹.

In Brazil, the increment of palliative care is still incipient, but meritorious initiatives are being developed in several centers and hospitals across the country, with promising reports. In addition, two organizations have important performance in the palliative care promotion: the Brazilian Society of Palliative Care (ABCP) and the National Academy of Palliative Care (ANCP).

The ABCP was founded in Sao Paulo, in October 1997, by psychologist Ana Georgia Cavalcanti de Melo, who gathered a group of interested professionals,

forming a scientific council to put into practice the goals of the association and to disseminate their philosophy, aggregating the palliative care services existing in Brazil, although not standardized yet, who offered assistance to patients off therapeutic possibilities in some scope: hospitalization, outpatient care unit and/or home admission.

ANCP was created in 2005 and led to advances in the professional regularization of the Brazilian palliative professional, as quality criteria were established for palliative care services, precise definitions were made of what is or is not palliative care and the discussion was referred to the ministries of Health and Education, in addition to the CFM and the Brazilian Medical Association (AMB).

ANCP, actively participating in the CFM's Technical Chamber on Terminality of Life and Palliative Care, helped developing two major resolutions governing the medical activity related to this practice. In 2009, for the first time in medical history in Brazil, the CFM included, in its new code of medical ethics, the palliative care as a fundamental principle. Since then, the ANCP struggles for the regularization of Palliative Medicine as medical area with AMB, and by the universalization of palliative care services in the Ministry of Health.

It lacks, however, a greater streamlining of these ideas with clarity and adequate incentive, as well as to advance in the regulation and standardization of palliative

care across Brazil. It becomes necessary also to prepare and invest in healthcare professionals' awareness that patients without cure need specific care, and palliative care is not just cost constraining measures.

Pain and suffering

Pain, in contemporary society, is unacceptable due to the observation of the abuse of self-medication, making painkillers consumption one of the pharmaceutical industry's greatest marketing assets. It should be noted that, currently, Brazil is one of the largest consumers of such drugs in the world and in most cases not prescribed by physicians.

However, the human being lives with the pain ever since. Since he is alive, the pain is part of everyday life of the person. The demonstration that something does not go well: it reflects an alarm about some dysfunction or that the body was assaulted or harmed. The pain and, yet, the symptom that leads patients most to doctors. Research indicates that more than 70 persons looking for doctors and health services are moved by this symptom ¹².

For a better understanding about the medical professionals' perception of pain, it is important to emphasize some aspects. First: the acute pain is treated with more ease and promptness by doctors; chronic pain (with more than six months long) does not have the same intensity of medical action.

Secondly: in their training, medical students have little depth on the topic, which is reflected in excessive parsimony in the prescription of more potent pain relievers particularly opiates, at the time of the future professional practice. This fear is generated by the fear of overdosing, difficulty in handling of analgesic drugs and superficial capacity to assess the algic state of patients and a possible risk of dependence. That resulted in a space created for a new specialty or area of expertise: pain medicine. It is lost, then, a knowledge that should be disseminated among all physicians, leaving without value the Latin maximum which is one of the pillars of medicine: *sedare dolorem opus divinus est* ¹³.

It is well known that in patients with advanced cancer the prevalence of pain reaches 90%; and with the acquired immunodeficiency syndrome (aids), around 50%. Therefore, pain is an extremely prevalent symptom in terminal patients. Their treatment must be a medical priority and this perception should be widely disseminated, as well as the appropriate training of involved professionals. It is worth remembering that patients under palliative care need special attention, since many have neurological changes, are elderly and often do not have condition of adequately referring his symptoms.

Saunders coined the term *total pain* to speak of suffering that a person undergoes not only by his physical damage, but for

the emotional, social and spiritual consequences that the vision of close death brings to him. Such a situation demands, according to her, a multi-professional treatment and not only medical.

The difficulty of Brazilian physicians in handling and prescribing powerful analgesic drugs is incomplete training in this area of physical pain, but also, visceral, neuropathic and psychogenic pain, points to an even greater failure in learning and conducting those pains that are not only within the body, but transcend the psychic and invade the soul of those who are under their care. Physicians' fragmentary training and, sometimes, reductionist has prevented adequate approach of pain and suffering of those under palliative care.

It is known that pain and suffering can be indistinct; however, if the physical pain is properly conducted and healed, the comfort provided to the ill person will allow him to have clarity and perhaps living with his ones, allowing him the necessary autonomy and tranquility to decide on the treatment ¹⁴. It should be added that he may provide the verbalization of his fears and anguish, as well as the manifestation of his convictions, making it possible to receive the specialized assistance from other professionals in the team, if he wishes ¹⁵.

Human dignity and dignifying death

Human being is biographical. His life story, including his family, profession, dreams, hopes and beliefs, is the essence of his existence ¹⁶. The fatal illness, which from the perspective of the subject that experiences it comes *suddenly*, makes life somewhat elusive. Marked by the perception of new time, shorter days before the imminent prospect of death, existence is revealed in the negotiation of that time that must be recovered, renovated and parsimoniously spent, since it is limited.

Abruptly, the patient realizes that his dreams of happiness and projects are under layers of suffering, pain and immobility. He finds himself finite and aware of the impossibility to delay the end of his life. This reality is new and unique, only experienced by the individual, with a complex elaboration and dependent on his whole life story.

How can the physician, acting with terminal patients, helping them to cross this pathway? How can the physician, feeling powerless, contribute correctly, providing him tranquility and hope to the patient? The truth must permeate the physician-patient relationship in all stages of the process of becoming ill and even more so when this declines toward death. The doctor's compassionate action cannot delete the truth, always told adequately, allowing the patient to have a correct awareness of his condition. This will allow him to collaborate in the treatment and to decide about it, with the other team members.

Communication is another major datum. The due clarity and adaptation of technical discourse and reality condition experienced by patients and their families will allow proper understanding and adherence to the proposed treatment. We must, in this situation, prospect to know how much the patient wants to be informed about his health. There is a considerable number of patients who did not want to know his actual state, and this attitude must be respected.

It is crucial that the involved professionals form a true multidisciplinary team and have the ability to evaluate the patient's capacity to decide about all matters that involve his illness, treatment and prognosis. This approach is not, and should not be, left only to the physician. Palliative care represents excellent field of synergy between physicians, psychologists, physiotherapists, nurses, social workers and others, in addition to religious persons^{17,18}, in order to offer the best for the patient.

A person who finds himself inexorably finite suffers. Deformed in his physical image, constrained by the dependency and feeling diminished by the disarray of elementary functions. Contributing to retrieve him and restore him to dignity dimmed by physical degradation is the scope of work of health teams, a not easy process, because it always passes by the respect to the patient's will about the treatment, at the time when, competently, he expresses himself.

The team should also consider the technically indicated intervention, to the extent that it is possible to recover damaged functions or minimize humiliating results, facilitating the patient's encounter with his beliefs and offering him, in the limit, all support in the psychological, family and religious areas^{17,18}. Thinking always as a professional, that such individual under medical care is a unique human being and should be seen as such.

Suffering itself exposes the individual to his own fragility, stealing his autonomy and individuality. This state of suffering if expressed, also, in the light of the characteristics that define it. Such situation implies changes of who is under care and needs suitable information, knowing his own reality, to decide what he wants. This action of continuously give information to the patient about his condition, mitigating his anguish and reducing vulnerability, is the central part of the idea of respecting the person in his individuality, allowing him to assume his intentions and decisions.

This reality requires a different health professional, more precisely the new type of physician, with advanced preparation from a technical point of view, but permeated with humanistic contents. This new professional shall be aware of the limits, even extended by technology; more prepared for teamwork, stripping himself of the technical-scientific arrogance, knowing that his patient needs all possible help.

Any human being's death is not an unworthy situation, but unworthy can be the care that he receives at the end of his life. Palliative care, in this perspective, has emerged in order to provide, with proper care, that the final stages of life of patients with incurable diseases end in humanized way, dignified and with absolute respect to the ill person ¹⁸.

Final considerations

Pain and suffering are inherent to human existence. It seems, in a philosophical and ethical perspective through beliefs and the unfathomable mysteries of difficult and complex questions without answers, the humanity shall remain prisoner of doubt regarding suffering.

The progress of medical science is the high tech advancement associated to health seemed to end this situation and the pain would be controlled. The *technification* of medicine with the introduction of modern technologies and potent drugs apparently controlled anguish and physical pain, giving physicians the feeling that the problem would be resolved and in such a way that it is considered *bad medicine* to leave a patient suffering pain. However, the continuous monitoring of terminal patients showed that only mitigating the pain is inadequate, because the suffering of such situation transcends the physical pain, although controlling it is, in fact, of paramount importance. It is fundamental to, detaching this patient from primordial suffering, identify and *treat* other pains and suffering that go beyond this dimension.

This fact appears more forceful when it involves patients with serious diseases or those living with incurable diseases, whose inexorable course leads to death. The palliative care has emerged as curative treatment option, with the innovative proposal to occupy the empty treatment of people who need to take control of his physical pain, and advance further in serving his full needs and respect his dignity.

This means having at the patient's disposal a multi-professional team and not just a physician, as well as the realization that changing parameters is needed between physicians and other professionals involved, in addition to adequate and systematized preparation since graduation. It represents, in parallel, new vision of life, death and medical care, since banks of medical schools, giving emphasis to medical care at the expense of occupational medicine to cure, when this is no longer possible.

Gracia believes that, analyzing the various elements involved in ethical issues relevant to palliative care, it evolves currently from *ethics of conviction* very close to general nursing care, whose basic principle was the blind obedience to professional authority, both in technical order as in ethics for the ethics of responsibility or ethics of care, where, quoting Gilligan says: *While the ethics of rights is a manifestation of equal respect, that balances the demands of another with mine, ethics of responsibility rests on an understanding that gives rise to compassion and care* ¹⁹.

Palliative care, perhaps because it is originally more related to nursing care and the *ethics of conviction* were gradually giving way to others more specific of ethics of responsibility. Gracia defends that, at the present time, the latter is winning space. However, he raises the thesis that a genuine ethics of palliative care should be developed. This way, the religious importance of holiness and sacredness of life, thriving the idea of

quality of life and dignifying death²⁰.

Care, solidarity and compassion are new words to be part of the medical and health teams' views in face the new realities to better treat patients in the final stages of life. Without any doubt, patients need more the integral and humanized care than the latest available technology!

Resumo Os avanços tecnológicos associados a medicina levam os médicos a terem como meta incansável vencer a doença e prolongar a vida. Contudo, para os pacientes sem possibilidade de cura, prolonga-se o sofrimento e o processo de morrer. Os cuidados paliativos destinam-se aos pacientes cuja enfermidade não mais responde ao tratamento, tendo como prioridade melhorar sua qualidade de vida mediante alívio da dor física e sofrimentos psicológicos, sociais e espirituais. Para a introdução deste conceito discute-se a mudança de paradigmas na formação dos profissionais de saúde, que representam nova visão da vida, da morte e do atendimento médico, sobrepondo-se o cuidar ao curar, quando isto não for mais possível. No estágio final da vida dos pacientes terminais busca-se manter digna e confortável a existência destes, até o último momento, tendo como pilares o atendimento multidisciplinar e o respeito a autonomia, integridade e dignidade do paciente.

Palavras-chave: Cuidados paliativos. Dor. Direito a morrer. Células-tronco.

Resumen

Sufrimiento y dolor en los cuidados paliativos: reflexiones éticas

Los avances tecnológicos asociados a la medicina, llevan a los médicos a tener como meta incansable vencer la enfermedad y prolongar la vida. A pesar de ello, para los pacientes que ya no tienen posibilidad de cura, se prolonga también el sufrimiento y el proceso de morir. Los cuidados paliativos se destinan a los pacientes cuya enfermedad ya no responde al tratamiento teniendo como prioridad mejorar su calidad de vida a través del alivio del dolor físico y los sufrimientos psicológicos, sociales y espirituales. Para la introducción de este concepto, se discute el cambio de paradigmas en la formación de los profesionales de salud, que representan una nueva visión de la vida, de la muerte y de la atención médica, sobreponiéndose el cuidar al curar, cuando esto último ya no sea posible. En la etapa final de la vida de los pacientes terminales, se busca mantener digna y comfortable la existencia de éstos hasta el último momento, teniendo como pilares la atención multidisciplinaria y el respeto a la autonomía, integridad y a la dignidad del paciente.

Palabras-clave: Cuidados paliativos. Dolor. Muerte con dignidad.

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It is worth stressing that the difficulty in establishing the terminality is not smaller or larger than other difficulties faced by professionals of medicine, when diagnosing a rare disease or opting for a treatment instead of others, knowing that an exact position could not bring distinct consequences for the patient. This is because, in medicine, it is not 100% certain. Thus, wanting the physicians to act with a terminal ill person with absolute certainty of the inevitability of death is not a valid argument to deny the legitimacy of orthotanasia, because the requirement is incompatible with the exercise of medicine, which cannot be obliged to cure the patient, but can undertake to give him the highest possible quality of life, according to his condition and existing technical resources. The resolution in question is therefore a manifestation of this new generation of ethics in medical sciences, breaking old taboos and decides to confront other problems realistically, with a focus on human dignity. In current medicine, there is a breakthrough in the treatment of terminally ill or serious pathologies in order to give the patient not necessarily more years of life, but, mainly, survival with quality. Medicine leaves, therefore paternalist, super-protecting era, that channeled his attention only to the disease and not to the ill person, in a real obsession for healing at any cost, and goes to a phase of greater concern with the well-being of the human being.