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THE IMPORTANCE OF THE IMPLEMENTATION OF PALLIATIVE CARE IN THE BRAZILIAN NATIONAL HEALTH SYSTEM

*A importância da implantação dos cuidados
paliativos no sistema único de saúde*

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ABSTRACT

The hospitalization of death and the Medicine technological development throughout the twentieth century made death an aseptic and solitary event that removed from the patient the autonomy over the process of dying itself. However, the population aging and the increase in non-transmissible are demanding that Medicine turns its attention to the patient and not only to the disease, stimulating the rethinking about the process of dying and encouraging the patient to reappropriate their own death. Based on bibliographic and normative research, and exploratory methodology, the present article intends to discuss the palliative care as a right to be guaranteed to the terminally ill patient who, in recognizing of the finitude of life, seeks in their final moments physical, mental and spiritual comfort. The resignification of death and the dying process are, today, necessary elements to guarantee the patient's autonomy over their own body and the quality of their life until the final moments, and, from this comes the importance of the Resolution n. 41/18, MS to the Brazilian National Health System.

Keywords

Autonomy; Palliative Care; Worthy Death; End of Life.

RESUMO

A hospitalização da morte e o desenvolvimento tecnológico da medicina ao longo do século XX tornaram-na um evento asséptico e solitário que retirou do enfermo a autonomia sobre o próprio processo de morrer. No entanto, o envelhecimento populacional e o aumento das doenças crônicas não transmissíveis estão exigindo que a medicina volte sua atenção ao doente, e não apenas à doença, estimulando o repensar sobre o processo de morrer e incentivando o enfermo a se reapropriar da própria morte. A partir de pesquisa bibliográfica e normativa e de metodologia exploratória, o presente artigo pretende discutir os cuidados paliativos como um direito a ser garantido ao enfermo terminal, que, ao reconhecer a finitude da vida, busca em seus momentos finais conforto físico, mental e espiritual. A resignificação da morte e do processo de morrer é hoje elemento necessário para garantir a autonomia do paciente sobre o próprio corpo e a qualidade de sua vida até os momentos finais, daí a importância da Resolução n. 41/2018 para o Sistema Único de Saúde brasileiro.

Palavras-Chave

Autonomia; Cuidados Paliativos; Morte Digna; Terminalidade da Vida.

Medicine aims
To cure sometimes,
To relieve often,
To comfort always
(Oliver Holmes, 1883)

Introduction: medical conduct in the face of the end of life

Death is inherent to life, it is inseparable from it and, therefore, it must be thought and discussed as all other aspects related to being alive. In this sense, Eroulths Cortiano Junior states that “it is not death that bothers us, especially because it - the biological process that it is - will arrive, whether we like it or not. It is the knowledge of death that bothers us”¹. For this reason, Evaldo A. D’Assumpção starts his study with the assumption that death is not a problem for those who leave, but for those who remain, because they are the ones who outrage, are surprised and are left with the weight of losses and possible blame².

And that is how Brazilian society is currently facing the issue. People do not talk about death, believing that this avoidance will keep them away, prevent and delay. However, when they encounter it, they are surprised, despair and realize that (many times) they do not even know the wishes of the sick person about the treatment to be offered, the organ donation or even if they would like to be buried or cremated.

In Brazil, the absence of discussion about death and dying is not only a cultural problem, but also a professional one, since health professionals are not prepared to deal with death; on the contrary, they are taught to fight for life, no matter how much suffering this may cause to the patient, a behavior that ends up being stimulated by new technologies.

Today, in the culture in which we are inserted, it seems that what does not cure does not serve, and the art of care, which has always accompanied doctors and caregivers, seems to have abandoned us on the basis of a science that is asked for accuracy, effectiveness and results in terms of overcoming disease, a science that in the face of death feels a failure. [...] The dimension of care, which includes active listening, approximation of what the patient lives, support in what cannot be solved, relief of the soul and not just of the body, sharing values, all of this has passed into the background, including we heard that exercising

¹CORTIANO JUNIOR, Eroulths. Preface. Aprender a morrer: o direito e nossa liberdade na hora de partir. In: PONA, Éverton Willian. *Testamento vital e autonomia privada: fundamentos das diretivas antecipadas da vontade*. Curitiba: Juruá, 2015.

²D’ASSUMPÇÃO, Evaldo Alves. *Sobre o viver e o morrer*. 2. ed. ampl. Petrópolis: Vozes, 2011.

this dimension is no longer up to the doctor. In a round-trip way, our society conforms to super-specialized doctors, even though they know nothing of humanism, and the doctor only reinforces this role, being extraordinary when we meet someone who, in addition to healing us, “know about us”, “understands us very well”.³

The fact is that, just as most Western cultures do not understand death well, doctors are also, for the most part, not trained to accept it. They are trained to face death, to heal, to save lives; when faced with the imminence of death, they do not know how to deal with it, often using useless treatments and techniques that prolong, without any practical and human sense, the patient’s life just because they are unable to admit the finitude of life.

And from this reality, from the social (cultural and religious), legal and professional indisposition in dealing with death, the controversial question arises as to how to care for terminally ill patients and accept their designs. The concepts of end of life and terminally ill patient are not precise.

Conceptualizing terminally ill patient is not easy to establish, although we are often faced with conceptual assessments by different professionals. Perhaps, the greater difficulty is in objectifying this moment, not in recognizing it [...]⁴.

It is the moment when “the patient becomes ‘irrecoverable’ and walks to death, without being able to reverse this walk”⁵. The end of life should not be associated exclusively with prognosis and quality of life. “A patient is terminal in a particular context of real possibilities and personal positions [...]”⁶.

Hence the need to understand the process of dying, not from the perspective of Medicine, but from the perspective of the patient, as well as what psychiatrist Elizabeth Kübler-Ross did in the 1960s in the United States and also Lady Cicely Saunders, who created in 1967 in London the St. Christopher’s Hospice, an institution designed exclusively to promote palliative care with a focus on health care medicine.

Palliative care, according to the World Health Organization (WHO), corresponds to:

³BERMEJO, José Carlos; BELDA, Rosa María. *Testamento vital: diálogo sobre a vida, a morte e a liberdade*. São Paulo: Loyola, 2015. p. 33.

⁴GUTIERREZ, Pilar L. O que é o paciente terminal? *Rev. Assoc. Med. Bras.*, São Paulo, v. 47, n. 2, p. 92-96, jun. 2001. p. 92. Available at: <https://www.scielo.br/pdf/ramb/v47n2/a10v47n2.pdf>. <https://doi.org/10.1590/S0104-42302001000200010>.

⁵*Id.*, *loc. cit.*

⁶*Id.*, *loc. cit.*

[...] an approach that improves the quality of life of patients (adults and children) and their families who face problems associated with life-threatening diseases. Prevents and relieves suffering through early identification, correct assessment and treatment of pain and other physical, psychosocial or spiritual problems⁷.

In addition, for D'Assumpção, palliative care is that which, having no primary intention of seeking a cure for the patient, which is out of the question from the medical point of view, has the fundamental objective of providing him with all the comfort and quality of life as long as he have (doctors = palliative care). Not only is the quality of life is evaluated, but also the quality of death⁸.

In this sense, Pessini and Bertachini highlight the etymology of the word “palliative”.

The term “palliative” is derived from the Latin *pallium*, which means “mantle”, “cloak”. It points to the essence of palliative care: relieving symptoms, pain, and suffering in patients with chronic-degenerative diseases or in the final stages, aiming at the patient in his globality of being and improving his quality of life. Etymologically, it means providing a mantle to warm up “those who are cold”, since they can no longer be helped by curative medicine⁹.

The terminal patient (chronic or acute) should be concerned not with the time of existence, but with the quality of the time that remains, and this must be guaranteed not only by the professional team that assists them and by the hospital services available, but by the law and, especially, by family members who accompany or represent him. This is part of what is called the humanization of the process of dying.

To understand suffering as something inherent to the terminal patient is to understand their autonomy to decide which course their treatment should take. And it is precisely in this aspect that family members tend to present themselves selfishly, pointing the finger at the patient who refuses treatment or opts for palliative care, calling him weak, as if the patient had simply given up fighting. That's not it! The patient who refuses or demands the suspension of certain treatments or opts for palliative care believes that he has suffered enough, is aware of the near end and wants a death without suffering, recognizing it as a natural process of his human condition. That way,

⁷WORLD HEALTH ORGANIZATION – WHO. *Palliative care*. Available at: <http://www.who.int/mediacentre/factsheets/fs402/en/>. Accessed on: 08 Oct. 2017.

⁸D'ASSUMPÇÃO, Evaldo Alves. *op. cit.*, p. 161.

⁹PESSINI, Léo; BERTACHINI, Luciana. Conhecendo o que são os cuidados paliativos: conceitos fundamentais. In: PESSINI, Léo; BERTACHINI, Luciana (Orgs.). *Encanto e responsabilidade no cuidado da vida: lidando com desafios éticos em situações críticas e de final da vida*. São Paulo: Paulinas; Centro Universitário São Camilo, 2011. p. 19.

the patient's clamor for palliative care is based on his main concern, which is whether he can resist with composure and dignity physical and psychological discomfort, chronic pain, dependence on other people, mutilation, and retaliation of self-esteem and the dehumanization that survival in a hospital produces¹⁰.

It is in this context that doctors and family members must understand the patient's autonomy to refuse or suspend futile treatments, to opt for palliative care, to conduct their own process of dying.

The fear of death, as culturally established in most Western societies, is the fear of life not lived, which makes it difficult to seek dignified death. The rejection of death makes it difficult to recognize the autonomy of the terminal patient to define the direction of his process of dying, invalidate the appropriation of the patient from the decision on his own end, calls into question dignified death (here understood as humanized death) and interferes, including, in discussions on the adoption and implementation of public policies related to palliative care.

Given this situation,

the good doctor is not the one who only meets social expectations, but the one whose behavior is centered on the losses that the person with a serious illness has suffered, and must grant responses as a human being to another human being in distress¹¹.

Analyzing the process of dying from the point of view of the patient is to seek the humanization of medicine (and death itself), establishing a moral commitment to patients from the recognition of their autonomy, without intending to cause death, but accept the finitude of life and promote the dignity of the human person until the final minute, including access to palliative care.

The present work deals with this discussion based on a bibliographic and normative study, conditioned to three major assumptions: (i) the transformations of the notions of death and the process of dying that occurred in the 21st century, of the aging population and the alteration of the main causes of death; (ii) the search for health guarantee also at the end of life; (iii) the adoption of palliative care as a public policy in Brazil based on Resolution no. 41/2018¹², from the Ministry of Health.

¹⁰ MENEZES, Renata Oliveira Almeida. *Ortotanásia: o direito à morte digna*. Curitiba: Juruá, 2015. p. 81.

¹¹ *Ibid.*, p. 81.

¹² MINISTÉRIO DA SAÚDE. *Resolução n. 41, de 31 de outubro de 2018*. Dispõe sobre as diretrizes para a organização dos cuidados paliativos, à luz dos cuidados continuados integrados, no âmbito do Sistema Único de Saúde (SUS). Available at: http://www.in.gov.br/materia/-/asset_publisher/Kujrw0TZC2Mb/content/id/51520746/do1-2018-11-23-resolucao-n-41-de-31-de-outubro-de-2018-51520710. Accessed on: 12 Jan. 2019.

The approach intended here is therefore limited to the beginning of debates on the adoption of palliative care as a public policy of the Brazilian National Health System (SUS), aiming to point out its positive aspects and its main challenges. Therefore, for the purposes of this article, the problem posed is precisely to seek to understand death and the process of dying in the 21st century and how social, technological and clinical transformations were decisive in the adoption of the public policy of palliative care in SUS, influenced by rethinking the right to a dignified death.

I. Death in the 21st century

At the end of the 19th century, due to the hospitalization of death and the doctor's paternalistic behavior, many patients was not even aware of their real state of health, being left in ignorance, especially regarding the imminent end of life.

At the beginning of the 20th century, the patient's ignorance was added to the prohibition of mourning and everything that in public life could remember death.

[...] the inconvenience of serious illness, the physical disgust that it proves, the need to hide it from others and oneself. In their moral conscience, the family confuses their unconfessed intolerance to the sordid aspects of the disease, with the demands of cleanliness and hygiene [...] ¹³.

The complete medicalization of the process of dying and the consequent easing of family suffering peaked in 1945, when scientific progress already pointed towards giving more attention to the disease than to the patient, indicating hospitalization for any situation, regardless of the severity of the disease. The hospital went from being a place of healing or where one died due to a therapeutic failure to being a place where death would occur naturally.

According to Ariès “the time of death was prolonged and subdivided at the same time [...]. Ancient signs, such as heart and breathing arrest, are no longer enough. They are replaced by a measure of brain activity, the electroencephalogram” ¹⁴. The time of death started to be extended by the will of the patient's doctor or relatives, disregarding the patient's own autonomy and dignity. Death, now enclosed, became distant, aseptic and lonely, abstracting any space for the choices, suffering and rituals of the patient. Death, as an enemy to be defeated, brought with it the utopia of human immortality.

¹³ARIÈS, Phillippe. *O homem diante da morte*. São Paulo: Unesp, 2014. p. 786.

¹⁴*Id. Ibid.*, p. 789.

The increasing hospitalization of death and the technization of medicine reached its peak at the end of the 20th century, to the point where the patient, even if he wanted to, could not die because was connected to machines in cold and lonely environments. The feeling of failure of the health teams is constant and the feeling of shame and helplessness of the families is increasingly evident. Not letting go, fighting to the last breath, seems to be the only option of doctors and family members¹⁵, at the risk of, not doing so, seem insensitive and disconnected from the dying person.

However, already in the first half of the 21st century, movements are developed that seek to humanize the process of dying and aim to rescue the patient's autonomy (as a fundamental right), allowing him to learn to die and how to die. These movements do not occur without reason. Medical technology distanced the doctor from the patient and from the social reality itself, because, while at the beginning of the 20th century people died of natural causes at 30, 40 years old, today they die from chronic diseases, neoplasms and degenerative diseases and the average life expectancy (in Brazil) is over 75 years old¹⁶.

The change in the main causes of death, with people now dying from chronic diseases that can last for decades, leads to another criticism. According to Jyh *et al.*, "the increased frequency of ICU admissions of patients with advanced chronic diseases, or with express limitation of efforts to support life, or of dying patients, produces ethical constraints and disorganizes health care systems"¹⁷. That's why Forte *et al.* inform that

Palliative care in ICU does not mean reducing the number of prescribed drugs and nursing procedures, neglecting scientific medical knowledge of signs and symptoms, or suspending information to family members during medical bulletin hours [...]¹⁸.

Palliative care in the ICU cannot represent the complete isolation of the patient, nor can it disregard their needs and those of their families. It is a comprehensive care that aims to reduce suffering in all its dimensions.

¹⁵See the controversial cases of babies Charlie and Alfie, in United Kingdom. See: ROSENVALD, Nelson. *A terminalidade da vida de um bebê*. Available at: <https://www.nelsonrosenvald.info/single-post/2017/07/04/A-terminalidade-da-vida-de-um-bebe>. Accessed on: 12 Jan. 2019.

¹⁶See IBGE statistics on the Brazilian population.. INSTITUTO BRASILEIRO DE GEOGRAFIA E ESTATÍSTICA – IBGE. *População*. Available at: <https://www.ibge.gov.br/estatisticas-novoportal/sociais/populacao.html>. Accessed on: 12 Jan. 2019.

¹⁷JYH, Juang Horng; MOOCK, Marcelo; DIAMANTE, Loraine Martins; FORTE, Daniel Neves; AZEVEDO JUNIOR, Renato. Terminalidade da vida. In: AZEVEDO JUNIOR, Renato; OLIVEIRA, Reinaldo Ayer. *Reflexões éticas em medicina intensiva*. São Paulo: CREMESP, 2018. p. 18.

¹⁸FORTE, Daniel Neves; KOCHI, Ana Claudia; OLIVEIRA, Reinaldo Ayer. Cuidados paliativos em unidade de terapia intensiva. In: AZEVEDO JUNIOR, Renato; OLIVEIRA, Reinaldo Ayer. *Reflexões éticas em medicina intensiva*. São Paulo: CREMESP, 2018. p. 31.

Therefore, it is not without reason that Resolution no. 2.156/2016¹⁹, of the Federal Council of Medicine (CFM), when establishing the criteria for admission and discharge in intensive care unit, determines not only that admission in an ICU should be based on “potential benefit for the patient, taking into account the medical indication” (art. 1, V), but also that patients in terminally ill disease, or dying, with no possibility of recovery, have only priority 5 (on a scale of 1 to 5) for ICU admissions (art. 6, §5º), and their admission into these units is only exceptionally justified, giving priority to their admission in palliative care units (art. 8).

And, precisely to avoid the undue prolongation of life, when therapeutic obstinacy is not a clear and conscious option for the patient himself and to avoid unnecessary constraints to him, the health team and family members, it is that the awareness of the finiteness of life is rescued and, with it, the fear of the process of dying indignantly in the face of the current stage of biotechnological development (with the use of medicines and treatments that can prolong life indefinitely²⁰). It is in this scenario that we seek to discuss what the limits to therapy are or should be, especially when it comes to terminal patients or with clear guidelines for choosing orthothanasia.

The new reality of diseases and treatments imposes the need to rethink the process of dying, seen no longer from the point of view of the disease, but from the patient’s point of view. To prolong the lives of terminally ill patients indefinitely, disregarding their desires is to impose selfish and unnecessary suffering on those who no longer have any prospect of cure or recovery.

It is in this scenario that the reappropriation of the process of dying by the patient is sought, recognizing their awareness and perception of their own death. Terminally ill patients require physical and spiritual comfort, not futile, expensive and ineffective treatments (therapeutic obstinacy). This must be the new parameter of death in the 21st century: dignity in dying, allowing the sick to die according to their own values and beliefs. This parameter needs to be present not only in the private health system, but also in public systems, such as the SUS.

Palliative care then comes with an option for the reappropriation of the process of dying by the patient himself and, therefore, should have as primary objectives:

¹⁹CONSELHO FEDERAL DE MEDICINA. *Resolução n. 2.156, de 17 de novembro de 2016*. Estabelece os critérios de admissão e alta em unidade de terapia intensiva. Available at: <https://sistemas.cfm.org.br/normas/visualizar/resolucoes/BR/2016/2156#search=%22uti%22>. Accessed on: 14 Oct. 2020.

²⁰See cases like that the Indian nurse who died after spending 42 years in a coma. (ENFERMEIRA indiana morre após passar 42 anos em coma. *Isto É*, São Paulo, 18 maio 2015. Available at: https://istoe.com.br/418614_ENFERMEIRA+INDIANA+MORRE+APOS+PASSAR+42+ANOS+EM+COMA/. Accessed on: 22 Jun. 2019).

- a. improve and integrate communication between health professionals and patients and their families;
- b. be careful with the signs and symptoms of patients at the end of life (*end of life*);
- c. provide psychosocial support to these patients and their families;
- d. offer technical and emotional support to ICU professionals, especially to the nursing team²¹.

Such objectives can be observed in article 4 of the Resolution MS n. 41/2018, which establishes the guiding principles of the organization of palliative care:

I - onset of palliative care as early as possible, together with the modified treatment of the disease, and start the investigations necessary to better understand and control stressful clinical situations;

II - promotion of pain relief and other physical symptoms, psychosocial, spiritual and existential suffering, including appropriate care for family members and caregivers;

III - affirmation of life and acceptance of death as a natural process;

IV - acceptance of the natural evolution of the disease, not accelerating or delaying death and repudiating diagnostic and therapeutic futility;

V - promotion of quality of life by improving the course of the disease;

VI - integration of psychological and spiritual aspects in patient care;

VII - offer a support system that allows the patient to live as autonomous and active as possible until the moment of his death;

VIII - offer a support system to help the family cope with the patient's illness and grief;

IX - multiprofessional and interdisciplinary teamwork to address the needs of patients and their families, including grief counseling, if indicated;

²¹JYH, Juang Horng; MOOCK, Marcelo; DIAMANTE, Loraine Martins; FORTE, Daniel Neves; AZEVEDO JUNIOR, Renato. *op. cit.*, p. 18.

X – sensitive and empathetic communication, with respect to truth and honesty in all issues involving patients, family members and professionals;

XI - respect for the self-determination of the individual;

XII - promotion of the free expression of preferences for medical treatment through an advance directive of will (DAV); and

XIII - collective effort to ensure the compliance of the will expressed by DAV.

Death, is no doubt, is closely linked to life, privacy, human existence and, therefore, it is necessary to dignify it, allowing the sick to plan it according to their values and beliefs. According to Forte *et al.*, “the transition from active care to care with palliative intention is a continuous process and its dynamics differs for each patient, avoiding the ‘all or nothing’ approach”²². Therefore, death should not be seen as a failure, but as a metaphysical event that recognizes it as inherent in life itself, forcing the human being to (re)learn to die.

II. Health in the end of life

According to Godinho,

the right to life consists of the most elementary of all human conditions. It is the fundamental premise of the existence of natural persons, of the right that supports all other rights. Addressing the right to life implies treating it in all its extension, at the beginning, in development, until the end²³.

Therefore, closely linked to the right to life is the right to dignified death, a right that manifests itself when human existence no longer finds dignified conditions. It is worth mentioning that there is no consensus on which right the dignified death is part. In this article, we opted the current that associates it with life (right to life) and, therefore, where there is no longer a dignified life, its holder should be granted the right to die without undergoing long, unnecessary and costly treatments not only from an economic point of view, but especially emotional²⁴.

²²FORTE, Daniel Neves; KOCHI, Ana Claudia; OLIVEIRA, Reinaldo Ayer. *op. cit.*, p. 31.

²³GODINHO, Adriano Marteleto. *Eutanásia, ortotanásia e diretivas antecipadas de vontade*. Curitiba: Juruá, 2016. p. 21.

²⁴On the subject see: SÁ, Maria de Fátima Freire; MOUREIRA, Diogo Luna. *Autonomia para morrer*. 2. ed. Belo Horizonte: Del Rey, 2015.

Among the human rights of the patient (founded on international human rights law), the right to a dignified death is related to the right to privacy (right to respect for private life) and palliative care is guaranteed as the right to not be subjected to torture or cruel, degrading or inhuman treatment or punishment. Godinho still maintains that

when proposing the expression “dignified death”, therefore, one must extract from it not the sense of allowing anyone to invoke a supposed subjective right to die or to ask for help from third parties to achieve such intent. Dying with dignity does not imply the granting of a right to request death, but an ethical requirement to allow the death of the terminally ill to come naturally, surrounded by support and comfort. The dignified death, therefore, is not refers to the supposed right to want death, but rather to the way of dying²⁵.

The fact is that, regardless of to consider the right to dignified death as a right linked to life or privacy, it mean a fundamental right, perfectly justified by the source value of the Brazilian legal order – the dignity of the human person (art. 1, III, CF/88²⁶) – and, therefore, a freedom as to existential choices that finds the broadest constitutional support.

So, when health no longer represents the “state of complete physical, mental and social well-being”, it is necessary to guarantee to the patient the right of choice (self-determination): to continue treatments that only prolong their life, without any efficacy or possibility of cure (Dyathanasia/therapeutic incarceration/therapeutic obstinacy) or to opt for treatments that relieve their physical and/or moral suffering, but that do not prevent the process of dying naturally (orthothanasia). And the choice must belong exclusively to the sick, since it is a freedom of existential choice.

It is in this context where the right to health at the end of life, care for the sick, respect for their choices, and recognition of the finiteness of life are discussed that movements that recognize palliative care as an integral part of fundamental health care emerge.

The terminality of life is faced in different ways by the patient, who, influenced by exclusively personal convictions, must have the right to choose how he wants to conduct his process of dying. Treating life as an absolute right implies disregarding death as one of its stages and imposing on the sick person disrespecting his autonomy and the dehumanization of death itself.

²⁵GODINHO, Adriano Marteleto. *op. cit.*, p. 83.

²⁶BRASIL. *Constituição da República Federativa do Brasil de 1988*. Available at: http://www.planalto.gov.br/ccivil_03/constituicao/constituicaocompilado.htm. Accessed on: 14 Oct. 2020.

This is the line of thought of the so-called vitalist current (from the principle of sacredness) Supporters of this current say that

“Man is sacred to man”, is being the eminent value of life, which is dignity of protection regardless of subjective or utilitarian interests, the natural support of all other human rights, that is, the transcendent reality that cannot be left at the disposal of its holder²⁷.

In other words, the right to life, absolute in its essence, does not include acts of disposition, even if there is no more dignity in life. There is only one right: the right-duty to live and its value cannot be put into perspective.

The self-determination recognized by the patient is today a key point in the discussions, in which it must be recognized that there is no duty to live at any cost and regardless of the quality of life. Yes, there is a right over one's own life that authorizes the person to make decisions according to the quality of his life after going through processes of clarification and reflection. It is about the principle of quality and, for its defenders the human life cannot be valued based only on biophysiological criteria, since it “would not identify itself with the human being, but only with the one that has certain characteristics or capacities of conscience, rationality or volition”²⁸. In that case, the value of life is recognized when it fulfills minimum existential conditions.

This is not to say that it could be conceived that some lives should be worth more than others, which would be absurd. It is said that there are circumstances in which prolonging life against the patient's will is causing him suffering and it is taking away the right to a dignified existence. The balance between one and the other is precisely in the patient's dignity (subjective element) and self-determination. That way,

an approximation between trends is perfectly feasible: it starts from the fundamental premise of the aspect of sacredness, which would avoid the increasing degradation of the protection of human existence, but at the same time it is recognized that the notion of quality of life, if well understood, it can contribute to the solution of limit situations, in which a rigid conception of the sacredness of life would be excessive²⁹.

And this is where it is possible to affirm, then, a right to health at the end of life, embodied in palliative care and not in an absolute medicalization of death, because

²⁷ GODINHO, Adriano Marteleto. *op. cit.*, p. 27.

²⁸ *Id. Ibid.*, p. 28.

²⁹ *Id. Ibid.*, p. 29.

the spectacular success of doctors in the fight against many situations that were mortal not so long ago created in doctors and the public, at least subconsciously, the notion that death could be overcome and that any situation, no matter how serious, should be treated intensively with the aim of preventing death³⁰.

Ensuring the dignity of life also in the process of dying is not imposing medical treatments at any cost, but ensuring quality and comfort in the end of life process. The obsession with excessive and ineffective medical measures in spite of the patient's wishes violates the principle of human dignity, being justified more by the search for the quantity of life than for his quality. "Dysthanasia, therefore, corresponds to the solitary apprehension of a human being, in a fruitless attempt to curb death, when this is no longer possible and even convenient"³¹. Dysthanasia does not artificially prolong life, but rather prolongs the process of dying, reducing life only to its biological dimension, dissociated from any qualitative analysis.

Palliative care, closely linked to the idea of orthothanasia, allows certain and inevitable death to manifest itself, preserving basic patient care. It is a measure that seeks to rehumanize the process of dying in the face of the technization of medicine and the hospitalization of death. Orthothanasia, therefore, does not seek death, because this process is already established. Rather, it aims to allow the acceptance of the end of life intermediated by care that guarantees physical, psychological and spiritual comfort to the patient, imposing the proportionality of medical treatments.

Palliative care brings with it the idea of ordinary life-sustaining measures (proportional means of health care), which "are usually available, inexpensive and less aggressive, commonly accepted as basic care due to the seriously and terminally ill"³². They are essential care, not intended to prolong the life of the terminal patient, but to maintain their dignity until the final moment. Thus, it can be said that the usefulness of a treatment can only be assessed in the concrete situation. To determine the futility of a treatment, Pellegrino established three major parameters:

a) Effectiveness: for each medical intervention, an estimate must be made of its ability to positively alter the natural history of the disease or symptom [objective criterion]. [...]; b) benefit: of a subjective character, it concerns what the patient considers to be valid or beneficial for him. [...]; c) burden: it concerns the physical, emotional, economic or social costs experienced by the patient who undergoes treatment³³.

³⁰SERRÃO, Daniel. Bioética, perspectiva médica. *Revista da Ordem dos Advogados*, Lisboa, ano 51, v. 2, p. 425, jul. 1991. Available at: <https://portal.oa.pt/upl/%7B2e848906-fb96-4c58-bb8e-05d78eeff16e%7D.pdf>.

³¹GODINHO, Adriano Marteleto. *op. cit.*, p. 73.

³²VILLAS-BÓAS, Maria Elisa. *Da eutanásia ao prolongamento artificial: aspectos polêmicos na disciplina jurídico-penal do final da vida*. Rio de Janeiro: Forense, 2005. p. 46.

³³PELLEGRINO, Edmund D. *Decision at the end of life: the use and abuse of the concept of futility*. p. 93. Available at: <http://www.uffl.org/vol10/pellegrino10.pdf>. Accessed on: 31 May. 2018.

The perfect proportion between these criteria demonstrates, in the concrete situation, the usefulness or not of a medical treatment, considering, before any decision making and after the process of clarification and reflection, the patient's own choice.

Having verified the end of life, the futility of some measures and the informed consent of the patient, the conduct to be adopted is that of beginning palliative care. "The meaning of palliative medicine is to extrapolate the physical dimension of a disease and also address 'the psychological, social and spiritual concerns of human existence.'"³⁴

Palliative care brings the notion of care to an extremely technical medicine, concerned with the patient, and not with the disease. Palliative medicine makes it possible to give priority to what is ethically and medically justified, not to what is medically possible. It is not a question of abandoning the sick, but of offering comfort when death is imminent. "Palliative medicine recognizes that dying means nothing more than the last and inevitable act of living"³⁵ placing the patient and the quality of his end of life as the only and exclusive priority.

For this reason, the principles that guide palliative care can be summarized in: promoting individualized and continuous comprehensive care for patients; involve the family in care; respect the patient's autonomy; impose an active concept of therapy; establish an enabling environment for patient care; perform multidisciplinary tasks by different professionals³⁶.

Putting the focus on the sick and not on the disease, palliative care must be established in private and public health systems at all levels of care. It is not a matter of opting for cost reduction, but of guaranteeing the greatest possible comfort to those for whom death is already presented as inevitable and imminent and who consciously choose to be the most appropriate treatment for their situation.

It should be noted that the adoption of palliative care must be the result of a dialogue between the patient and his doctor or, in case of incapacity, between the representative (legal or conventional) of the patient and his optional. Palliative care cannot be imposed, as it is the result of a rational and thoughtful choice aimed at patient comfort, not institutional care. For this reason, article 41, sole paragraph, of the Code of Medical Ethics provides that

in cases of incurable and terminal illness, the doctor must offer all available palliative care without undertaking useless or obstinate diagnostic or therapeutic actions, always taking into account the

³⁴GODINHO, Adriano Marteleto. *op. cit.*, p. 98.

³⁵*Id. Ibid.*, p. 99.

³⁶PESSINI, Léo. *Distanásia: até quando prolongar a vida*. 2. ed. São Paulo: Centro Universitário São Camilo; Loyola, 2007. p. 379.

expressed will of the patient or, in his impossibility, that of his legal representative³⁷.

The philosophy of care does not advocate for the patient's abandonment, nor that for his death surrounded by melancholy or sadness. Conversely, the philosophy of care determines that the accompaniment of the terminally ill is permeated by dialogue, solidarity and relief from physical and psychological suffering; is the comprehensive and humanized care that guarantees to the patient autonomy and quality in the process of dying.

III. The adoption of palliative care as a public policy: brief considerations from Resolution no. 41/2018, from the Ministry of Health

Considering the demographic transition caused by the ageing population and the epidemiological modification of the causes of mortality in the 21st century, as well as the National Program for the Humanization of Hospital Care (PNHAH), the Tripartite Commission of the Ministry of Health approved Resolution MS no. 41/2018, providing for guidelines for the organization of palliative care within the scope of SUS at all levels of health care (art. 5^{or}). It is worth highlighting that palliative care already existed in SUS; the novelty lies in its specific regulation and in the definition as a public health policy, with important guidelines.

Saito and Zoboli say that

due to its progressive and degenerative evolution, chronic health conditions generate demand for continuous and permanent assistance - which includes palliative care (PC) - in the different points of the health care network (RAS). Continuous assistance in chronic health conditions involves attention in the silent moments of the disease, when it has evolved without the perception of the person who will suffer the degeneration of quality of life³⁸.

And therein lies the new challenges of medicine and public health policies. Historically, health systems have been organized to meet the curative dimension of medicine, that is, to “respond to acute conditions or episodes of acute chronic conditions”³⁹. However, with demographic and epidemiological changes, another dimension starts to demand attention: the palliative, which is not intended only for

³⁷ CONSELHO FEDERAL DE MEDICINA – CFM. *Resolução n. 2.217, de 01 de novembro de 2018*. Aprova o Código de Ética Médica. Available at: <https://sistemas.cfm.org.br/normas/visualizar/resolucoes/BR/2018/2217>. Accessed on 22 Jun. 2019.

³⁸ SAITO, Danielle Yuri Takauti; ZOBOLI, Elma Lourdes Campos Pavone. Cuidados paliativos e atenção primária à saúde: scoping review. *Rev. Bioét.*, Conselho Federal de Medicina, Brasília-DF, v. 23, n. 3, p. 593-607, dez. 2015. p. 594. Available at: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1983-80422015000300593&lng=en&nrm=iso. <http://dx.doi.org/10.1590/1983-80422015233096>.

³⁹ SAITO, Danielle Yuri Takauti; ZOBOLI, Elma Lourdes Campos Pavone. *op. cit.*, p. 594.

terminal patients, but for all patients with chronic or acute disease (art. 2MS no. 41/2018), which also includes their social protection.

However, the insertion of palliative care in public policy programs is not easy.

The attitudes and skills needed to promote high quality CP [palliative care] overlap with those needed for excellent PHC [primary health care]: communication skills; understanding of the reality and peculiarities of the patient's way of life; commitment to the integral and integrated care of the patient and the family; attention to psychosocial and spiritual issues; emphasis on quality of life and patient independence; respect for the patient's values, objectives and priorities in the management of his health condition; offering care in the community, due to cultural diversity; collaboration with other professionals, including⁴⁰specialists.

Organizing a public system that requires these skills for its success is not easy, but it is a challenge that is immediately imposed on the most diverse Brazilian public policies with the effect of Resolution MS no. 41/2018. The resolution presents important guidelines and seeks to improve the system, including palliative care in SUS care units. Thus, palliative care becomes part of a reflected public policy, which provides for the introduction of mechanisms to ensure the effectiveness and wide availability of these programs - also aiming to improve Brazil's position in the ranking quality of death from Economist Intelligence Unit, currently 38th out of 40 countries surveyed, ahead of only Uganda and India⁴¹.

The intervention highlighted here is based on the rehumanization of medicine and the care process, permeated by ethical and legal responsibility towards the patient and informed by the dignity of the human person, the necessary multi-disciplinary action and open dialogue with the patient. So, having recognized the problem by the Ministry of Health itself, it is now necessary to seek the inclusion of the theme in government agendas that guarantee the consolidation of palliative care as part of SUS public policies, with the provision of ample information from the diagnosis and the clinical network enough to care for patients who choose to adhere to such care.

According to Oliveira,

the humanization of health care as a process of transformation of institutional culture recognizes and values the subjective, historical and socio-cultural aspects of users and professionals, as well as important institutional functions for understanding problems

⁴⁰*Id., loc. cit.*

⁴¹BRASIL fica entre os piores em ranking de tratamentos paliativos a pacientes terminais. *BBC Brasil*, 06 out. 2015. Available at: <http://noticias.uol.com.br/saude/ultimas-noticias/bbc/2015/10/06/brasil-fica-entre-piores-em-ranking-de-tratamentos-paliativos-a-pacientes-terminais.htm>. Accessed on: 06 Oct. 2015.

and developing actions that promote good working conditions and quality of service⁴².

Even before MS Resolution no. 41/2018, the humanization of health was already a transversal policy of all the integrating instances of SUS, which value aspects of the subjective, collective and social dimension of care and management of the public system.

Among the fundamentals for inserting palliative care in SUS, the following stand out:

(i) Ordinance SAS/MS no. 1,083/2012, which provides for the clinical protocol and therapeutic guidelines for chronic pain;

(ii) Ordinance GM/MS no. 2/2017, annex IX, which institutes the National Policy for the Prevention and Control of Cancer in the Health Care Network of People with Chronic Diseases within the scope of SUS; Annex X, which establishes the National Policy for Comprehensive Child Health Care under the SUS; Annex XI, which establishes the National Health Policy for the Elderly; Annex XII, which approves the National Primary Health Care Policy of SUS; Annex XXIV, which establishes the guidelines for the organization of the hospital component in the HealthCare Networks; Annex XXV, which approves the National Policy on Integrative and Complementary Practices in SUS; and Annex XXVIII, which provides for the financing and implementation of the Basic Component of Pharmaceutical Assistance within the scope of SUS;

(iii) Ordinance of Consolidation GM/MS no. 3/2017, which establishes the organization of long-term care to support the Urgent and Emergency Care Networks and other Health Care Thematic Networks of SUS;

(iv) Ordinance of Consolidation GM/MS no. 5/2017, GM/MS dealing with home care and hospitalization services;

(v) Ordinance of Consolidation GM/MS no. 6/2017, which deals with the financing of the basic and specialized component of pharmaceutical assistance;

(vi) Resolution CFM no. 1,805/2006, which provides for orthothanasia;

(vii) Resolution CFM no. 1995/2012, which provides for the use of advance directives of will (on health);

(viii) Resolution CFM no. 2,156/2016, which establishes the criteria for admission and discharge from the intensive care unit; and

⁴²OLIVEIRA, S.G. Humanização da assistência: um estudo de caso. *Revista de Administração em Saúde*, v. 9, n. 35, p. 55-62, abr./jun. 2007. [s.p.].

(ix) the recommendation of the 67th World Health Assembly (2014) for the development, strengthening and implementation of evidence-based palliative care policies.

What is now being seen is the requirement that palliative care be understood as a guarantee of rights already provided for the National Humanization of Health Care and Health Care Management Policy⁴³, in the National Humanization Policy (PNH) of SUS⁴⁴ and the National Assistance Pain and Palliative Care Program⁴⁵, treated not only as national programs, but also as part of Brazilian health policy.

Understanding the Palliative Care from the perspective of guaranteeing rights in line with the National Humanization of Health Care and Health Care Management Policy (PNH) is thinking beyond the control of pain and symptoms, from children to the elderly, extending care from the perspective of preventing limit situations as, for example: patients abandoned by the family, families in disputes over assets and inheritance, disputes over pension for death (cases of patients with more than one family), difficulties in accessing a hospital vacancy, patients who die and leave minors without definition of guard, patients from the streets who die as destitute and whose funeral is more agile due to the bureaucracy of health institutions, patients who cannot maintain adequate nutrition, patients living in areas at risk and with precarious housing etc.⁴⁶.

Therefore, the model of assistance or care implies the need to review spaces, the organization of management and technologies, multiprofessional relationships, the training and qualification of professionals who will work in palliative care, communication models and the organization of the health actions, changing the focus from the health recovery to the care and comfort of the patient, guidelines clearly established by Resolution MS no. 41/2018.

For this reason, Article 1, sole paragraph, of the resolution makes it clear that palliative care should be part of the integrated continuous care offered in the scope of SUS. This means that the resolution, although it is only intended to establish guidelines for the insertion of palliative care in health policies, is not limited to

⁴³ MINISTÉRIO DA SAÚDE - MS. Secretaria de Atenção à Saúde. Política Nacional de Humanização da Atenção e Gestão do SUS. *HumanizaSUS na atenção básica*. Brasília-DF, 2009. (Série B. Textos Básicos de Saúde). Available at: http://bvsms.saude.gov.br/bvs/publicacoes/humaniza_sus_atencao_basica.pdf. Accessed on: 14 Oct. 2020.

⁴⁴ MINISTÉRIO DA SAÚDE - MS. *Política Nacional de Humanização - PNH*. 1. ed. 1. reimpr. Brasília-DF, 2013. http://bvsms.saude.gov.br/bvs/publicacoes/politica_nacional_humanizacao_pnh_folheto.pdf. Accessed on: 14 Oct. 2020.

⁴⁵ MINISTÉRIO DA SAÚDE. *Portaria n. 19, de 03 de janeiro de 2002*. Available at: http://bvsms.saude.gov.br/bvs/saudelegis/gm/2002/prt0019_03_01_2002.html. Accessed on: 14 Oct. 2020.

⁴⁶ FROSSARD, Andrea. Os cuidados paliativos como política pública: notas introdutórias. *Cad. EBAPE.BR*, Rio de Janeiro, v. 14, ed. esp., artigo 12, p. 640-651, jul. 2016.

determining the de-hospitalization (home care) of the chronic or terminal patient, nor to impose on the family the duty to care of this patient, which in itself is considered an important advance. According to Ugarte,

palliative care services, in addition to hospital care, must be structured in an integrated network that provides for: palliative care outpatient; palliative care day unit; inpatient units in palliative care; palliative care advisory groups; hospital units specialized in palliative care; palliative care hostels⁴⁷.

Another important point in Resolution MS n. 41/2018 is that palliative care has been anchored in an important tripod: the integration of palliative care in the SUS structure; training and communication of health teams and dialogue with society; and the availability of treatments and medications necessary for their effectiveness. Each of these assumptions poses enormous challenges, especially when it comes to public health. These challenges must be overcome with the development of specific programs to be implemented in the coming years.

With Resolution MS no. 41/2018, the public authority recognizes that palliative care, as a public policy, is broader than the mere de-hospitalization of the terminally ill, adhering to the World Health Organization recommendation, which states that: palliative care must provide relief from pain and other distressing symptoms; affirming life and considering death as a normal process; respect the process of dying, not rushing or delaying it; offer a support system for the patient to live with quality until the final moments; offer a family support system to deal not only with the disease, but also with grief; use a multidisciplinary approach (from diagnosis) seeking, as far as possible, the quality of the patient's final life⁴⁸.

So, in order to develop a public palliative care policy,

government policies are needed to recognize and encourage the integration of palliative care in the structure and financing of the National Health System; educational policy that promotes the training of health professionals, community volunteers and the general public; drug policy that guarantees the availability of essential drugs for the management of pain and other physical and psychological symptoms in the final phase of life, especially the opioid analgesics⁴⁹.

⁴⁷ UGARTE, Olívia. *Contexto normativo dos cuidados paliativos no SUS*. Trabalho de Conclusão de Curso apresentado ao Curso de Especialização em Saúde Coletiva e Educação em Saúde, Universidade Federal do Rio Grande do Sul, Porto Alegre, 2014. p. 20-23.

⁴⁸ WORLD HEALTH ORGANIZATION – WHO. *Palliative care*, cit.

⁴⁹ UGARTE, Olívia. *op. cit.*, p. 16.

With the development of these dimensions, it is possible to recognize palliative care as an important field of health care throughout the SUS service network, determining its planning and its integration into public systems (principle of comprehensive care) with specific sector policies, since it is not just a therapeutic option, but the patient's right understood in their own rights to life, privacy and health and in the dignity of the human person. Therefore, the main merit of Resolution MS no. 41/2018 is precisely to recognize the impacts of epidemiological and biotechnological changes on the process of dying; affirm the patient's autonomy over his existential choices and guarantee access to that choice throughout the public health network.

Final Considerations

The real failure of contemporary medicine is not impotence in the face of certain diseases, but the dehumanization of the process of dying and the encouragement of therapeutic obstinacy. Faced with the hospitalization of death and its consequent technization, it is necessary to resume the dialogue between doctor, patient and family; the recognition of the patient's autonomy and the search for a dignified death promote the (re) humanization of the process of dying, realizing the dignity of the human person in its fullness, since they allow a previous approach to the theme. In this sense, Jaramillo highlights that

it is not a matter of suggesting the adoption of an obsessive depressive posture about death. But if we want to become masters of our own death in order to be able to exercise our freedom and our autonomy in having the conditions in which we would like personal death to occur, it is essential to think about it beforehand, anticipate it in fantasy, imagine it, prepare us for its arrival in order to assimilate it in our life as a reality - it is not an easy task, certainly, but it is necessary⁵⁰.

For this reason, to the acute or chronic terminal patient must be guaranteed the right to determine how he wishes to live the time he has left, how in that time he will deal with relationships, with whom he wants to share this intimate moment. Only the sick person, according to his own values and beliefs, can decide what meanings the most diverse medical treatments will have for him, what life conditions he can tolerate, what he seeks as a quality for his final moments of life.

Death is not a supernatural monster that waits in the shadows to throw itself by surprise at us to steal our life and, with it, everything we love and care about. In contrast to, death

⁵⁰JARAMILLO, Isa. F.; MENDONZA-VEGA, Juan; SANTOYO TÉLLEZ, Saúl. Opções para morrer humanamente. In: JARAMILLO, Isa F. (Org.). *Morrer bem*. São Paulo: Planeta do Brasil, 2006. p. 163.

is a part of life itself, its final stage, from which we cannot run away and from which no one can escape, because in the mechanisms of life there is always, for all living beings, the device that must end these mechanisms as soon as they have completed certain steps⁵¹.

It is in dialogue and communication that the very meaning of life will be constructed, even if it is intended for the moment of death. To ignore palliative care as a public health policy and as one of the instruments for achieving the patient's self-determination and dignity is to deprive him not only of the fundamental right to self-determination and dignified death, but also of the feeling of self-control. It is to impose on him a duty to live that has no moral or legal support. It is to prevent him from becoming a person, successively annulling his personality through selfish limitations of his freedom.

The implementation of palliative care at all levels of health care in the Brazilian Unified Health System and the guidelines established in Resolution MS no. 41/2018 should be a priority at a time when the technization of medicine resumes more concern with diseases and the body than with the patient himself, his autonomy and his dignity.

References

ARIÈS, Phillippe. *O homem diante da morte*. São Paulo: Unesp, 2014.

BERMEJO, José Carlos; BELDA, Rosa María. *Testamento vital: diálogo sobre a vida, a morte e a liberdade*. São Paulo: Loyola, 2015.

BRASIL fica entre os piores em ranking de tratamentos paliativos a pacientes terminais. *BBC Brasil*, 06 out. 2015. Available at: <http://noticias.uol.com.br/saude/ultimas-noticias/bbc/2015/10/06/brasil-fica-entre-piores-em-ranking-de-tratamentos-paliativos-a-pacientes-terminais.htm>. Accessed on: 06 Oct. 2015.

CORTIANO JUNIOR, Eroulths. Preface. Aprender a morrer: o direito e nossa liberdade na hora de partir. In: PONA, Éverton Willian. *Testamento vital e autonomia privada: fundamentos das diretivas antecipadas da vontade*. Curitiba: Juruá, 2015.p. 15-17.

D'ASSUMPÇÃO, Evaldo Alves. *Sobre o viver e o morrer*. 2. ed. ampl. Petrópolis: Vozes, 2011.

ENFERMEIRA indiana morre após passar 42 anos em coma. *Isto É*, São Paulo, 18 maio 2015. Available at: https://istoe.com.br/418614_ENFERMEIRA+INDIANA+MORRE+APOS+PASSAR+42+ANOS+EM+COMA/. Accessed on: 22 Jun. 2019.

⁵¹*Id., loc. cit.*

FORTE, Daniel Neves; KOCHI, Ana Claudia; OLIVEIRA, Reinaldo Ayer. Cuidados paliativos em unidade de terapia intensiva. In: AZEVEDO JUNIOR, Renato; OLIVEIRA, Reinaldo Ayer. *Reflexões éticas em medicina intensiva*. São Paulo: CREMESP, 2018. p. 29-37.

FROSSARD, Andrea. Os cuidados paliativos como política pública: notas introdutórias. *Cad. EBAP.BR*, Rio de Janeiro, v. 14, ed. esp., artigo 12, p. 640-651, jul. 2016.

GODINHO, Adriano Marteleto. *Eutanásia, ortotanásia e diretivas antecipadas de vontade*. Curitiba: Juruá, 2016.

GUTIERREZ, Pilar L. O que é o paciente terminal? *Rev. Assoc. Med. Bras.*, São Paulo, v. 47, n. 2, p. 92-96, jun. 2001. Available at: <https://www.scielo.br/pdf/ramb/v47n2/a10v47n2.pdf>. <https://doi.org/10.1590/S0104-42302001000200010>.

HOLMES, Oliver. *Medical essays*. New York: Dossier Press, 1883.

INSTITUTO BRASILEIRO DE GEOGRAFIA E ESTATÍSTICA – IBGE. *População*. Available at: <https://www.ibge.gov.br/estatisticas-novoportal/sociais/populacao.html>. Accessed on: 12 Jan. 2019.

JARAMILLO, Isa. F.; MENDONZA-VEGA, Juan; SANTOYO TÉLLEZ, Saúl. Opções para morrer humanamente. In: JARAMILLO, Isa F. (Org.). *Morrer bem*. São Paulo: Planeta do Brasil, 2006. p. 163-190.

JYH, Juang Horng; MOOCK, Marcelo; DIAMANTE, Loraine Martins; FORTE, Daniel Neves; AZEVEDO JUNIOR, Renato. Terminalidade da vida. In: AZEVEDO JUNIOR, Renato; OLIVEIRA, Reinaldo Ayer. *Reflexões éticas em medicina intensiva*. São Paulo: CREMESP, 2018. p. 17-28.

MENEZES, Renata Oliveira Almeida. *Ortotanásia: o direito à morte digna*. Curitiba: Juruá, 2015.

MINISTÉRIO DA SAÚDE - MS. *Política Nacional de Humanização - PNH*. 1. ed. 1. reimpr. Brasília-DF, 2013. http://bvsm.sau.gov.br/bvs/publicacoes/politica_nacional_humanizacao_pnh_folheto.pdf. Accessed on: 14 out. 2020.

MINISTÉRIO DA SAÚDE - MS. Secretaria de Atenção à Saúde. Política Nacional de Humanização da Atenção e Gestão do SUS. *HumanizaSUS na atenção básica*. Brasília-DF, 2009. (Série B. Textos Básicos de Saúde). Available at: http://bvsm.sau.gov.br/bvs/publicacoes/humaniza_sus_atencao_basica.pdf. Accessed on: 14 Oct. 2020.

OLIVEIRA, S.G. Humanização da assistência: um estudo de caso. *Revista de Administração em Saúde*, v. 9, n. 35, p. 55-62, abr./jun. 2007.

PELLEGRINO, Edmund D. *Decision at the end of life: the use and abuse of the concept of futility*. Available at: <http://www.uffl.org/vol10/pellegrino10.pdf>. Accessed on: 31 May. 2018.

PESSINI, Léo. *Distanásia: até quando prolongar a vida*. 2. ed. São Paulo: Centro Universitário São Camilo; Loyola, 2007.

PESSINI, Léo; BERTACHINI, Luciana. Conhecendo o que são os cuidados paliativos: conceitos fundamentais. In: PESSINI, Léo; BERTACHINI, Luciana (Orgs.). *Encanto e responsabilidade no cuidado da vida: lidando com desafios éticos em situações críticas e de final da vida*. São Paulo: Paulinas; Centro Universitário São Camilo, 2011. p. 19-55.

ROSENVALD, Nelson. *A terminalidade da vida de um bebê*. Available at: <https://www.nelsonrosenvald.info/single-post/2017/07/04/A-terminalidade-da-vida-de-um-bebe>. Accessed on: 12 Jan. 2019.

SÁ, Maria de Fátima Freire; MOUREIRA, Diogo Luna. *Autonomia para morrer*. 2. ed. Belo Horizonte: Del Rey, 2015.

SAITO, Danielle Yuri Takauti; ZOBOLI, Elma Lourdes Campos Pavone. Cuidados paliativos e atenção primária à saúde: scoping review. *Rev. Bioét.*, Conselho Federal de Medicina, Brasília-DF, v. 23, n. 3, p. 593-607, dez. 2015. Available at: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1983-80422015000300593&lng=en&nrm=iso. <http://dx.doi.org/10.1590/1983-80422015233096>.

SERRÃO, Daniel. Bioética, perspectiva médica. *Revista da Ordem dos Advogados*, Lisboa, ano 51, v. 2, p. 419-428, jul. 1991. Available at: <https://portal.oa.pt/upl/%7B2e848906-fb96-4c58-bb8e-05d78eeff16e%7D.pdf>.

UGARTE, Olivia. *Contexto normativo dos cuidados paliativos no SUS*. Trabalho de Conclusão de Curso apresentado ao Curso de Especialização em Saúde Coletiva e Educação em Saúde, Universidade Federal do Rio Grande do Sul, Porto Alegre, 2014. 45p.

VILLAS-BÔAS, Maria Elisa. *Da eutanásia ao prolongamento artificial: aspectos polêmicos na disciplina jurídico-penal do final da vida*. Rio de Janeiro: Forense, 2005.

WORLD HEALTH ORGANIZATION – WHO. *Palliative care*. Available at: <http://www.who.int/mediacentre/factsheets/fs402/en/>. Accessed on: 08 Oct. 2017.

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