

f_death_in_search_of_autonomy_and_dignity_at_the_end_of_life.pdf

de revista artigo90

Data de envio: 27-jun-2025 09:39AM (UTC-0700)

Identificação do Envio: 2706939413

Nome do arquivo: f_death_in_search_of_autonomy_and_dignity_at_the_end_of_life.pdf (332.1K)

Contagem de palavras: 6617

Contagem de caracteres: 36495

On the (in)equality of death: in search of autonomy and dignity at the end of life

Sobre a (des)igualdade da morte: em busca de autonomia e dignidade no fim da vida

Cynthia Pereira de Araújo*
Flavia Danielle Santiago Lima**

Abstract

Does death make us equal? This article seeks to answer the proposed question by reviewing the theoretical debate around dignity at the end of life, considering the social determinants of health, which have an impact on inequality in access to palliative or supportive care. For this, the deductive method is used with bibliographic-documentary research of exploratory-descriptive character. It is concluded that there are two intrinsically related dimensions of a right to quality or dignity at the end of life, which would contemplate the civil-political right to autonomy and the socio-economic rights that ensure autonomy and unrestricted access to these services, as an ultimate attempt of equality.

Keywords: Death. Social determinants of health. Inequality. Human dignity.

Resumo

A morte nos iguala? O presente artigo busca responder à questão proposta através da revisão do debate teórico em torno da dignidade no fim da vida, considerando os determinantes sociais de saúde, que repercutem em desigualdade no acesso a cuidados paliativos ou suportivos, limitando a autonomia individual. Para tanto, utiliza-se o método dedutivo com pesquisa bibliográfico-documental de caráter exploratório-descritivo. Conclui-se que há duas dimensões intrinsecamente relacionadas de um direito à qualidade ou dignidade do fim da vida, que contempla o direito civil-político à autonomia e os direitos prestacionais que asseguram autonomia e acesso irrestrito a estes serviços, como tentativa última de igualdade.

Palavras-chave: Morte. Determinantes sociais de saúde. Desigualdade. Dignidade Humana.

1 Introduction: the awareness of death as the definer of the human being

All living beings have in common the fact that, sooner or later, they will die. The inevitability of death is a given and necessary component of life itself, even if eventually forgotten or neglected. The awareness of death, however, is the privilege of human beings and nothing can equate them more than the knowledge of the impossibility of altering their finitude.

This equality, however, doesn't mean much about life expectations and conditions for accessing end of life. Remembering death as a certain event with an uncertain date can mean, individually, a commitment to the present and the acceptance that, for no one, there is any guarantee of another day, much less of any future. But, in populational terms, people can die more or less, better or worse, with too much or none autonomy, pain and suffering.

However, if birth and life are widely treated and recognized in legal terms, this is not the case with this inevitable element of existence. Substantive and analytical constitutional norms, inserted in the Western philosophical tradition that have incorporated dignity as a radiating element of rights (KANT, 2003), are often concerned with the procedural and material dimensions of human life, forgetting death as a fundamental aspect of this process.

* Doutora em Direito pela PUC-Minas (2019, Teoria do Direito). Fez doutorado-sanduiche na Universität Vechta (Alemanha), com enfoque em Filosofia (bolsista CAPES/DAAD pelo Programa de Cooperação Bilateral Brasil-Alemanha - PROBRAL II). Membro dos Grupos de Pesquisa JUSPOLÍTICA - Diálogos, Historicidades e Judicialização de Políticas (Direito/UPE) e Direito e Razão Prática (PUC-Minas). Bacharel em Direito (UFMG). Mestre em Direito (PUC-Minas). Advogada da União. E-mail: cynthia.paraújo@gmail.com

** Professora da Faculdade de Direito da Universidade de Pernambuco (UPE/Recife). Professora permanente do Programa de Pós-Graduação em Direito da Faculdade Damas. Líder do Grupo de Pesquisa JUSPOLÍTICA - Diálogos, Historicidades e Judicialização de Políticas (Direito/UPE). Pós-Doutorado em Direito pela Universitat de València/ Espanha. Mestre e Doutora em Direito Público pela Universidade Federal de Pernambuco/UFPE. Advogada da União. E-mail: flavia-santiago@uol.com.br

When talking about death in this context, one generally thinks not only about the moment when life ends, but also about the process that precedes it, especially when the quality of that process is highlighted. Thus, it looks more appropriate to refer to it as the *end of life*.

This article intends to deepen the subject, in a study that starts from a theoretical approach, with the deductive method, suggesting two intrinsically related dimensions of a right to quality or dignity at the end of life, after the recognition that inequality is a fact of life and death. The given hypothesis is that the conjugation among the civil-political right towards autonomy and the socio-economic rights that ensure autonomy and unrestricted access to palliative or supportive care could turn unequal existences into more equal ones.

2 Death that uneven us

With the eradication and control of the diseases responsible for decimating the greatest number of lives in the past centuries, humanity has seen its life expectancy increase considerably. It has also seen that this outcome has the process of aging as its counterpart, with new diseases, especially the chronic ones. In this sense, historical experience shows that "disease is one of the conditions of existence of our species that, despite all its achievements, could not escape the limits of its biological nature" (SALGADO, 2011, p. 86).

The general increase in life expectancy does not mean, naturally, that different places submitted to different conditions have the same pattern of increase. If in European countries, the average has recently crossed the 80-year limit, there are African countries that cannot break the 50-year barrier.

These variables are technically treated from the expression "social determinants of health" (SDH), which imply the recognition that "*la salud y la enfermedad están determinadas por aspectos que van más allá de los de orden biológico, principalmente por aspectos de orden económico, político, cultural y ambiental*" (TOVAR, 2011, p. 209).

Or, according to the terms of the World Health Organization (WHO)

Los determinantes sociales de la salud son las circunstancias en que las personas nacen, crecen, viven, trabajan y envejecen, incluido el sistema de salud. Esas circunstancias son el resultado de la distribución del dinero, el poder y los recursos a nivel mundial, nacional y local, que depende a su vez de las políticas adoptadas.

Los determinantes sociales de la salud explican la mayor parte de las inequidades sanitarias, esto es, de las diferencias injustas y evitables observadas en y entre los países en lo que respecta a la situación sanitaria. (OMS, 2019)

In countries like Brazil, the size and social inequality - and, consequently, the inequality of health determinants - mean that there are totally different realities regarding life expectations. Elements such as race, gender and sexual orientation make the data even more disparate, conditioning or limiting the very individual freedoms and autonomy:

Inequalities in health are considered unfair when they are the product of situations that are beyond the control of individuals and that limit the exercise of the 'individual freedom' (agency) recognizing that, according to the socio-economic position - understood as a product of the interaction between the level of education, the type of occupation, the income, the gender, the ethnicity / exposure to racism and the social class - the degree of choices of lifestyle varies" (BORDE *et al.*, 2015, p. 849).

The articulation between individual and social elements is addressed in the two types of "social determinants of health" recognized by the WHO: structural and intermediate. The former have an impact on health equity and well-being through their action on intermediate determinants, as they "generate and reinforce social hierarchies that define power, prestige and access to resources through education, work and income and, thus, they configure material circumstances (living and working conditions, etc.)". The latter, in turn, refer to elements classified as (i) behavioral and biological, (ii) material (such as living and working conditions, food and housing) and (iii) psychosocial factors. It is in this universe that an important issue is inserted: the inequality of access to the health system, which shows that even the public entity can collaborate to deepen inequalities (BORDE *et al.*, 2015, p. 844-5).

In this context, discrimination is seen in its most diverse manifestations (direct and indirect; intersectional and multidimensional; unconscious and organizational and institutional, structural and intergenerational). The intergenerational issue, regarding the right to life and expectations concerning the moment of its extinction, is important in a context of societies that privilege the youth. But, from the perspective of the recognition of legal positions,

structural discrimination, contemplated in the "regular operation of social institutions", causes "disadvantages at different levels and in different sectors of the individuals' lives". Therefore, the State itself can promote inequalities, with evident repercussions on the individual autonomy, considering that "a discriminatory act not only denies equal treatment, but also limits the possibility of autonomous action" (MOREIRA, 2017, p. 29).

Although studies aimed at assessing horizontal inequality in access to health (the general principle that people with the same health needs should have similar access to health services, as a result of equality) have observed a drop in these rates until 2008, as a consequence of integration and access public policies, inequities persist (MACINKO; LIMA-COSTA, 2012).

For example, research carried out by the *Instituto de Pesquisa Econômica Aplicada* (IPEA) in 2009 shows the regional disparities, i.e. for every 1000 inhabitants in the South and Southeast regions, there are 3.7 doctors and nurses, while in the North the rate is 1., and in the Northeast 2.4. These numbers lead to a perverse reality: in the South and Southeast the number of medical consultations is higher, and the number of hospitalizations is lower (BRASIL, 2019).

In this sense, although the current life expectation of Brazilians is 80 years of age for women and 73 for men, this is far from meaning that certain populations can effectively expect such longevity.

This finding does not just mean that certain groups are closer to death. It also means that elements whose indicator or component is the general life expectancy – such as a country's Human Development Index or the person's own classification as elderly – may not represent anything to a significant part of the population. And, more, they will have the exercise of their autonomy limited or even unachievable when they approach their death.

3 Death that can make us equal

Although there may be – and there actually is – interference from external factors in the incidence of certain diseases, such as the so-called carcinogens, once certain diagnoses are known, people submitted to vastly different realities have very similar prognoses. The access to resources, including the highest technology, promotes sporadic and marginal benefits, and, therefore, terminality equals people who, in theory, had different life expectations.

In other words, people who could expect greater longevity, due to social or structural privileges, are as close to death as those whose life expectancy was below the population average.

The equality produced in this sense, however, refers only to the temporal aspect. The identification of a reserved prognosis leads to the probability of death in a certain time, but the quality of the end of life of patients affected by the same diseases varies greatly.

3.1 The idea of a good death

The quality of the end of life of patients with life threatening diseases has been popularized under the idea of "good death" or "dignified death". But talking about patients with advanced cancer, for example, it is not necessarily talking about people who are in their last days. Many will live weeks even months. A significant part will live more than a year. Although this period is the end of his/her life, the end of life is still life (ARAÚJO, 2019).

Hence the possible inappropriateness of using expressions centered on death for discussions that are not connected to topics such as euthanasia and assisted suicide, that is, that are not concerned with the decision-making power of a certain milestone for ending life. Thus, it is more appropriate to talk about quality or dignity at the *end of life*.

Some concepts are extremely important in this context. Medical futility, therapeutic obstinacy and dysthanasia relate to a common universe of meaning referring to the exaggerated prolongation of a patient's agony, suffering and death, without any real possibility of altering a health condition. The Portuguese term "ortotanásia" – orthothanasia –, on the contrary, refers to death at the right time, when the doctor can no longer interfere with the lethal outcome, but it also does not interfere to postpone it. It means to act in such a way that certain and inevitable death manifests itself, without being provoked or postponed (ARAÚJO, 2019).

In this sense, according to article 12 of the Principles of European Medical Ethics, approved in 1987 by the International Conference of the Orders of Doctors and Organizations with similar duties, "the doctor may, in the case of an incurable and terminal illness, limit himself to mitigate the patient's physical and moral suffering, providing him with the appropriate treatments and preserving his quality of life as much as possible". Before that, the Council of

Europe Assembly Recommendation on the rights of the sick and the dying No. 779, 1976, had already affirmed the patient's rights to dignity and integrity, to information, to appropriate healing and not to suffer in vain (PEREIRA, 2012, p. 39).

In Brazil, in 2006, the Federal Council of Medicine issued Resolution 1805, through which:

1st. The physician is allowed to limit or suspend procedures and treatments that prolong the life of the terminally ill patient, of serious and incurable illness, respecting the will of the person or his legal representative.

§1. The physician has the obligation to inform the patient or his legal representative about the appropriate therapeutic modalities for each situation.

§2. The decision referred to in the caput must be substantiated and recorded in the medical record.

§3. The patient or his legal representative is guaranteed the right to request a second medical opinion.

The normative act was questioned through a Public Civil Action filed by the Federal Public Ministry (Case No. 2007.34.00.014809-3), which required the declaration of nullity of the CFM Resolution, for confusing the concepts of orthoethanasia and euthanasia. The lawsuit was sentenced, considering the authorial request to be unfounded, thus, recognizing the constitutionality of the norm and, therefore, of orthoethanasia.

Dysthanasia, in turn, is expressly prohibited by the Brazilian Code of Medical Ethics, which provides, among its fundamental principles (Chapter I) that, "in irreversible and terminal clinical situations, the physician will avoid performing unnecessary diagnostic and therapeutic procedures and will provide patients under their care all appropriate palliative care". In addition, under the terms of article 41, sole paragraph, of the same diploma,

in cases of incurable and terminal illness, the physician must offer all available palliative care without undertaking useless or obstinate diagnostic or therapeutic actions, always taking into consideration the patient's expressed will or, in his impossibility, that of his legal representative.

There are, however, between the two extremes, situations whose delimitation is imprecise, escaping the exclusive medical authority and depending definitively on the patient's decision. It is the individual's right to refuse, initiate or continue treatments that are likely to result in real gains for the patient, so that they are not clearly considered as futile, that is, that do not constitute dysthanasia. For the realization of this right, it is necessary, first of all, to guarantee the patient's autonomy, which requires the patient's understanding of the severity of his/her illness, the accurate prognosis and the possible risks and benefits of the available medical interventions.

3.2 Autonomy: reality or legal fiction?

It can be said that death is the real taboo of the Western world (CARDOSO, 2010, p. 41). Although, in recent years, there has been a growing movement of redemption of the issue, the difficulty of most people, especially in countries such as Brazil, is notorious for discussing death, mainly in concrete terms – someone's own death, the death of loved ones. Thus, reflections on the proximity of the end of life are generally postponed until they are inevitable, which often happens due to the communication of serious diseases.

If, on the one hand, social or structural privilege guarantees general greater longevity for certain groups, on the other hand, it guarantees, at least in theory, greater autonomy for patients. Indeed, vulnerable groups have, in general, greater difficulty in accessing education and information, necessary for difficult medical conversations. The potential vulnerability of autonomy, in these cases, is especially important, given the findings that doctors overestimate the prognosis of end-of-life patients (CHRISTAKIS, 2000), that communication between doctors and patients is potentially flawed, and that even well-educated patients have inadequate understanding of the possible benefit of medical treatments for their diseases, notably the potential for cure or significant increase in longevity (ARAÚJO, 2019, p. 100).

This situation is aggravated by the lack of minimum conditions for understanding and doubts about subjects that are already overly complex in nature. If a well-educated person can be deceived by the real meaning of the result of a particular medical examination – which represents a certain percentage or the reduction of a tumor or even a complete remission, e.g. – the individual with little or no training may not be able to understand even basic information about his/her illness.

In view of this reality, the physician's obligation to obtain the patient's free and informed consent to perform procedures and treatments ends up having a purely formal connotation, since it is impossible to speak of effective

consent without adequate understanding. In this context, patients undergo treatments that they would not have accepted, had they understood its real cost-benefit, which compromises the quality of the end of life.

3.3 Unrestricted access to palliative or supportive care as an ultimate attempt of equality

Difficulty in accessing measures that alleviate – or even end – the pain and suffering of patients at the end of life is possibly the biggest factor of inequality related to death, especially early death. On the other hand, the reduction of this difficulty, in the short and medium term, requires much less incentive and resources, compared to the other factors.

The World Health Organization defines palliative care – or supportive care – as the approach that foresees the promotion of the quality of life of people with life-threatening diseases, and of the entities that face, together, the problems associated with them (ARAÚJO, 2019, p. 160). For this, “prevention and relief of suffering, through the early identification, the correct assessment and the treatment of pain and other physical, psychosocial, emotional and spiritual problems” are proposed (SILVA, 2015, p. 373).

In 2014, the World Health Organization and the World Palliative Care Alliance – WPCA (Worldwide Palliative Care Alliance) published the Global Atlas of Palliative Care at the End of Life, in which the access to palliative care, including the access to pain relief, was recognized as a human right.

In addition, there are studies which demonstrate that the early start of palliative care management significantly improves the patient’s understanding of his prognosis over time, which impacts decisions, including on active treatment, at the end of life (ARAÚJO, 2019, p. 172).

Therefore, there is an urgent need for the institution and the development of a culture of care. In the referred Global Atlas of Palliative Care at the End of Life, it is recommended that all medical schools include basic training on the subject and that continuing professional education includes the study of palliative care for trained health professionals (WORLDWIDE PALLIATIVE CARE ALLIANCE, 2014, p. 27).

Among the specific recommendations for state governments included in that Atlas, are the development of a comprehensive budget to increase access to palliative care services for all who need it is comprised, integrating them into health and community systems; and ensuring that palliative care is integrated into specific and appropriate national policies (WORLDWIDE PALLIATIVE CARE ALLIANCE, 2014, p. 72-73).

Although measures involving budget allocation are always subject to resistance, the integration of palliative care may prove to be even surplus, given the reduction in high-tech therapies and hospital admissions.

One of the essential points in providing palliative care concerns the supply of essential drugs, especially opioids, about which there is still a lot of misinformation:

Access to opioid medication for pain control is an enormous problem worldwide. Eighty per cent of the world’s population lacks adequate access to opioid medications for pain control. Australia, Canada, New Zealand, the United States, and several European countries account for more than 90% of the global consumption of opioid analgesics. (WORLDWIDE PALLIATIVE CARE ALLIANCE, 2014, p. 29)

Thus, it is necessary to ensure that opioid analgesics are available, as they are critical for effective pain relief for cancer patients. Both the World Health Organization and the International Narcotics Control Council recommend that opioids be available to patients with moderate to severe pain, even though there is, at the same time, the necessity to prevent abuse in their use (CHERNY *et al.* 2013, p. xi8).

It is important to highlight that, in Brazil, the Tripartite Inter-Management Commission Resolution No. 41, published in the Federal Official Gazette in 2018, provides guidelines for the organization of palliative care in SUS – the Brazilian national health system – at any level of the Health Care Network. Health (Article 5th). However, essential aspects for the actual realization of a palliative care policy that serves the entire population were relegated to the uncertainty of subsequent regulations, including the form of financing, which, according to article 8th of the resolution, should “be the object of a tripartite agreement, observing the planning and organization of continuous care integrated in the RAS” (ARAÚJO, 2019, p. 178).

4 Equality in dignity: personal autonomy and the right to existential benefits

The Universal Declaration of Human Rights (1948) brings the dignity “inherent to all members of the human family” and the “equal and inalienable” rights as “the foundation of freedom, justice and peace in the world”. At

1 a regional level, the American Convention on Human Rights (San Jose Pact of Costa Rica, 1969) provides that "every human person has the right to respect of his/her honor and the recognition of his/her dignity" (art. 11, § 1).

Human dignity as a central aspect of legal orders is a phenomenon that was expanded after the World War II, despite previous precedents (Germany, 1919; Portugal, 1933; Ireland, 1934; Brazil, 1934), in the face of the horrors practiced under the Nazi regime (SARLET *et al.*, 2015).

Concerning issues more closely related with health, a law was issued in 1933 for the "prevention of offspring with hereditary diseases", which determined the sterilization of people with hereditary diseases predicted therein, as well as of chronic alcoholics (NUERNBERG MILITARY TRIBUNALS, 1951, p. 243).

Despite the opposition of the church, many of these people were eliminated in euthanasia centers under the guise of "death by mercy", including hundreds of thousands of people with mental illness (ARAÚJO, 2015). Roseman records that the first time that gas was used as an instrument was precisely for the killing of psychiatric hospital patients (ROSEMAN, 2003, p. 32).

The horrors of ideology and elimination procedures adopted during the Nazism were such that, at the end of World War II, it was registered, for the institution of the International Military Courts, that human rights had been trampled on by the State in a way that shocked the very "sense of humanity" (NUERNBERG MILITARY TRIBUNALS, 1951, p. 982).

At the internal level, constitutionalism bet on the incorporation of moral content in the normative structure, through the statement of principles. In this way, the complex relations between law and morality was redefined, moving away from the parameter of the classical legal positivism. The constitutionalization of moral values under the normative formula of principles opened a wide margin for the recognition of the influence of this ethical order on the positive law. More than normative species, there is the centrality of the principles in the constitutional order. Under this conception, therefore, the axiological dimension in law is rehabilitated, due to the influence of a principle considered as universal: human dignity.

As Fabre (2000) recalls, the conversion of an originally moral value into constitutionalized law implies in the recognition that this right is sufficiently relevant to legally debilitate citizens and legislators from enacting rules that violate these rights, that is, to change people's legal situation, forbidding them by law to do certain things, or not, providing them certain things by law. Considering the importance of protecting legal positions such as autonomy and well-being, these are worthy of this insulation in the Constitutions.

Based on several regulations that provide for the aforementioned principle, the current Brazilian Constitution is characterized by its strong democratic leaning, supported by the election of predetermined values, such as human dignity and equality. The defenders of "constitutional openness" maintain, even, the prominence and centrality of the principle of human dignity, which constitutes a pole of attraction for "more and more new rights reflecting the constitutional-democratic fashion, which multiply in the direct reason of the insurgent conflicts in the social environment and the insatiable demands for legal positivization" (CASTRO, 2005, p. 13-16).

Considering its mention in art. 1 of the Federal Constitution, the dignity of the human person is the foundation of the Brazilian Republic, in addition to being referenced on several occasions in the Constitution.

The concept of human dignity is originally associated with the second expression of Kant's categorical imperative, which states: "Act in such a way that you always treat humanity, whether in your own person or in the person of any other, never simply as a means, but always and the same time as an end" (KANT, 2009, p. 73).

As with human dignity, the prohibition against discrimination is also positivized as a prohibition clause based on non-exhaustive and multidimensional criteria, in article 3^o, IV, of the CF. The norms of Article 3^o, section IV, of the Constitution, set down the prohibition of any form of discrimination and the promotion of the common good.

Alongside the regulation, the dignity of the human person is interpreted as:

The intrinsic and distinctive quality recognized in each human being that makes him/her worthy of the same respect and consideration on the part of the State and the community, implying, in this sense, a set of fundamental rights and duties which protect the person not only against any and all acts of degrading and inhumane nature, but also guaranteeing the minimum existential conditions for a healthy life, in addition to providing and promoting their active and co-responsible participation in the destinies of their own existence and life in communion with other human beings, through due respect for other beings that make up the network of life (SARLET, 2004, p. 67).

¹ Prevention of Progeny with Hereditary Diseases (Gesetz zur Verhuetung Erbkranken Nachwuchses).

Human dignity is also redefined by its consequences: (i) in the equal rights of all individuals; (ii) in guaranteeing the independence and autonomy of human beings (which should not be treated as objects), (iii) in the need to protect their inalienable rights and, finally, (iv) in the inadmissibility of any denial of means for personal development or the imposition of conditions considered subhuman (FLORES-VALDÉS, 1990, p. 149).

Its statement has a twofold character, establishing this fundamental duty for multiple recipients, as to oblige both, the State, and the society, to respect and protect it. Although, in addition to its fundamentality, it is understood that the positivization of dignity takes on a prescriptive and descriptive sense, a relationship with the social rights of service is identified, considering that "the lack of minimum material conditions for man, damages the exercise of freedom, and the State must not only restrain it, but also actively protect human life, which is the very reason for the State's existence" (BARCELLOS, 2011, p. 229).

Regarding the relations among human dignity, personal autonomy, and material benefits, applied to the field of bioethics, there is a useful discussion around the articulations and distinctions between rights, especially related to its warranty.

Frias and Lopes start from the discussion of the operability of human dignity as a structuring principle of legal orders promoted by Ruth Macklin, as it would be a "vague repetition of already existing notions", so that it would be more productive to replace it with the notion of personal autonomy or its expectation, due to its terminological precision, confronting authors who understand autonomy as an obscure aspect of dignity and those who argue that dignity is possible without autonomy.

In the end, they articulate that dignity could be defined as a combination of "personal autonomy and the conditions to develop and exercise it", in a contemplative proposal of the suggestion of this article:

Dignity should not be understood as the positive affirmation of an intrinsic property, which generates inaccuracies and arbitrariness, but rather as a normative statement about an acquired property, which requires conditions to develop and be exercised.

Dignity is the property that people have because they are able to decide on their own goals, personal autonomy. Such property justifies the requirement that the fundamental interests of people are protected by guaranteeing a minimum of basic conditions for their existence, an existential minimum (FRIAS; LOPES, 2015, p. 667-8)

The guarantee of civil and political rights, such as autonomy, depends on the protection of socio-economic rights – often under the formula of public policies, such as the requirement for palliative or supportive care. Thus, both legal positions are at the same level of fundamentality for a right to dignity at the end of life. As Bilchitz (2007) recalls, without respect for the two sets of rights (civil / political and socioeconomic), a society cannot claim to treat individual lives as being of equal importance: the measure of any decent politic.

Social rights aim at guaranteeing material equality, since they assume, with their concretization, the purpose of ensuring to the individuals not only their survival, but also full and dignified insertion in the societal life. Thus, they are glimpsed in the list of the fundamental rights, alongside with the negative rights, given that there is no point in enacting a list of freedoms, without the corresponding guarantee of a minimum necessary for human life. Literature frequently explores this interdependent relationship, in order to express the fundamentality of these rights, as in the example that the exercise of effective political freedom by citizens is related, in part, to the guarantee of education (BONAVIDES, 1999, p. 369).

Likewise, dignity at the end of life can be articulated in a view that limits interference with personal and positive autonomy, with regard to the characterization of rights granted by the state, as a result of the provisions of arts. 196 and 230 of the Federal Constitution:

5 Equating death is actually equating life

The necessary changes so that people from different regions, races, gender, sexual orientation and classes have similar life expectations go through transformations in all areas of society, as recognized by the WHO

² "Art. 196. Health is the right of all and the duty of the State, guaranteed through social and economic policies aimed at reducing the risk of disease and other grievances and universal and equal access to actions and services for their promotion, protection and recovery."

Art. 230. The family, society and the State have a duty to support the elderly, ensuring their participation in the community, defending their dignity and well-being and guaranteeing them the right to life."

Commission on Social Determinants of Health. According to this Commission, the mitigation of these differences depends on measures that can be structured in 3 main axes: "improving the daily living conditions", "fighting against unequal distribution of power, money and resources" and "measuring and analyzing the problem" to consider new strategies (OMS, 2019).

However, it is not necessary to wait for a new scenario to be designed for these people to have equal treatment at least at the end of their lives, so that the State itself does not constitute an aggravating agent of inequalities, moving away from the objectives established by the constituent for the Federative Republic of Brazil: building a free, just and solidary society; eradicating poverty and marginalization and reducing social and regional inequalities and promoting the "good of all, without prejudice of origin, race, sex, race, age and any other forms of discrimination".

Even liberal authors like John Rawls understand the existence of "constitutional foundations", which involve both "fundamental principles that specify the general structure of government and the political process" and the "equal basic rights and liberties of citizenship that legislative majorities must respect", so that the minimum social provision for the basic needs of all citizens must be ensured, as an essential element of a Constitution" (RAWLS, 1993, p. 227-9).

The historical aspiration around the democratic, constitutional and social state of law, supported by the recognition of human dignity, repels human suffering, degradation of life, blindness to marginality and discrimination (ARANGO, 2003).

If the necessary measures to build a more just and egalitarian society permeates decisions that involve profound structural changes and the mobilization of different actors and institutions, the development of a culture of care that guarantees dignity to patients with life-threatening diseases depends on awareness and adequate training, rather than large investments and political arrangements. This culture, which disseminates and effectively institutes palliative care in SUS (*Sistema Único de Saúde*, Brazilian Public Health System), would be sufficient, however, to confer the minimum equality previously denied, still in life, even at the end of it.

References

- ARANGO, Rodolfo. Basic social rights, constitutional justice, and democracy. *Ratio Juris*, Oxford, v. 16, n. 2, p. 141-154, jun. 2003.
- ARAÚJO, Cynthia Pereira de. **Nazismo e o conceito de não positivismo jurídico**. Curitiba: Juruá, 2015.
- ARAÚJO, Cynthia Pereira de. **Existe direito à esperança?: saúde no contexto do câncer e fim de vida**. 2019. Tese (Doutorado em Direito) - Pontifícia Universidade Católica de Minas Gerais, Belo Horizonte, 2019.
- BARCELLOS, Ana Paula de. **A eficácia jurídica dos princípios constitucionais: o princípio da dignidade da pessoa humana**. 3. ed. Rio de Janeiro: Renovar, 2011.
- BILCHITZ, David. **Poverty and fundamental rights: the justification and enforcement of socio-economic rights**. Oxford: Oxford University Press, 2007.
- BONAVIDES, Paulo. **Teoria do Estado**. São Paulo: Malheiros, 1999.
- BORDE, Elis; HERNANDEZ-ALVAREZ, Mario; PORTO, Marcelo Firpo de Souza. Uma análise crítica da abordagem dos determinantes sociais da saúde a partir da medicina social e saúde coletiva latino-americana. *Saúde Debate*, Rio de Janeiro, v. 39, n. 106, p. 841-854, set. 2015.
- BRASIL. Instituto de Pesquisa Econômica Aplicada. **Comunicado do IPEA n. 129 - Presença do Estado no Brasil: federação, unidades e municipalidades**. Brasília: IPEA, 2012. Available at: http://www.ipea.gov.br/portal/images/stories/PDFs/comunicado/120110_comunicadoipea129.pdf. Access in: 01 nov. 2019.
- CARDOSO, Juraciara Vieira. **Eutanásia, distanásia e ortanásia: o tempo certo da morte digna**. Belo Horizonte: Mandamentos, 2010.
- CASTRO, Carlos Roberto Siqueira. **A constituição aberta e os direitos fundamentais: ensaios sobre o constitucionalismo pós-moderno e comunitário**. Rio de Janeiro: Forense, 2005.

CHERNY, N. I. *et al.* The Global Opioid Policy Initiative (GOPI) project to evaluate the availability and accessibility of opioids for the management of cancer pain in Africa, Asia, Latin America and the Caribbean, and the Middle East: introduction and methodology. **Annals of Oncology**, Oxford, v. 24, Supplement 11, p. xi7-xi13, 2013.

CHRISTAKIS, Nicholas A.; LAMONT, Elizabeth B. Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study. **BMJ**, [s.l.], v. 320, p. 469-473, 19 feb. 2000. Available at: https://www.researchgate.net/publication/12636322_Extent_and_determinants_of_error_in_doctors'_prognoses_in_terminally_ill_patients_Pro prospective_cohort_study. Access in: 10 dez. 2021.

FABRE, Cecile. **Social rights under the constitution: government and the decent life**. Oxford: Oxford University Press, 2000.

FLORES-VALDÉS, Joaquín Arce y. **Los principios generales del derecho y su formulación constitucional**. Madrid: Civitas, 1990.

FRIAS, Lincoln; LOPES, Nairo. Considerações sobre o conceito de dignidade humana. **Revista Direito GV**, São Paulo, v. 11, n. 2, p. 649-670, dez. 2015.

KANT, Immanuel. **A metafísica dos costumes**. Tradução: Edson Bini. Bauru: EDIPRO, 2003.

KANT, Immanuel. **Fundamentação da metafísica dos costumes**. Tradução: Paulo Quintela. Lisboa: Edições 70, 2009.

MACINKO, James; LIMA-COSTA, Maria Fernanda. Horizontal equity in health care utilization in Brazil, 1998–2008. **International Journal for Equity in Health**, [s.l.], v. 11, n. 1, p. 11-33, 2012. Available at: <https://www.arca.fiocruz.br/bitstream/ricict/7663/1/Horizontal%20equity%20in%20health%20care%20.pdf>. Access in: 11 dez. 2021.

MOREIRA, José Adilson. **O que é discriminação**. São Paulo: Casa do Direito, 2017.

NUERNBERG MILITARY TRIBUNALS. **The justice case. Nuernberg. October 1946 – April 1949**. Washington: Government Printing Office, 1951. v. 3. (Trials of War Criminals – Under Control Council Law n. 10).

ORGANIZAÇÃO MUNDIAL DA SAÚDE. **Determinantes sociais de la salud**. Genebra: OMS, 2019. Available at: <https://www.paho.org/es/temas/determinantes-sociales-salud#:~:text=La%20Organizaci%C3%B3n%20Mundial%20de%20la,condiciones%20de%20la%20vida%20cotidiana%22>. Access in: 11 dec. 2012.

PEREIRA, André Gonçalo Dias. Valor do consentimento num estado terminal. In: ASCENSÃO, José de Oliveira (coord.). **Estudos de direito da bioética**. Coimbra: Almedina, 2012. p. 33-61.

RAWLS, John. **Political liberalism**. New York: Columbia University Press, 1993.

ROSEMAN, Mark. **Os nazistas e a solução final: a conspiração de Wannsee – do assassinato em massa ao genocídio**. Tradução: Maria Luiza X. de A. Borges. Rio de Janeiro: Jorge Zahar Editor, 2003.

SALGADO, Carolina Martínez. Abrir la epidemiología. In: EIBENSCHUTZ, Catalina; TAMEZ, Silvia; GONZÁLEZ, Rafael (org.) **¿Determinación social o determinantes sociales de la salud?**. México, DF: Universidad Autónoma Metropolitana, 2011. p. 71-90.

SARLET, Ingo Wolfgang. **Dignidade da pessoa humana e os direitos fundamentais na Constituição Federal de 1988**. Porto Alegre: Livraria do Advogado, 2004.

SARLET, Ingo Wolfgang; MARINONI, Luiz Guilherme; MITIDIERO, Daniel. **Curso de direito constitucional**. 4. ed. São Paulo: Saraiva, 2015.

SILVA, Marcelle Miranda da *et al.* Visitando hospices na Alemanha e no Reino Unido na perspectiva dos cuidados paliativos. **Escola Anna Nery Revista de Enfermagem**, Rio de Janeiro, v. 19, n. 2, p. 369-375, abr./jun. 2015.

Cynthia Pereira de Araújo e Flavia Danielle Santiago Lima

TOVAR, Maurício Torres. Los determinantes sociales de la salud: herramienta para la acción política por el derecho a la salud. In: EIBENSCHUTZ, Catalina; TAMEZ, Silvia; GONZÁLEZ, Rafael (org.). **¿Determinación social o determinantes sociales de la salud?**. México, DF: Editora Universidad Autónoma Metropolitana, 2011. p. 207-204.

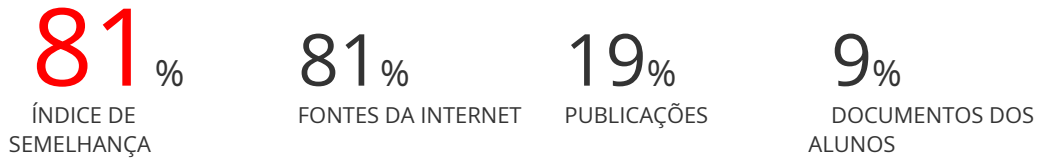
WORLDWIDE PALLIATIVE CARE ALLIANCE. **Global atlas of palliative care at the end of life**. New York: The World Health Organization, 2014. Available at: <http://www.thewhpc.org/resources/global-atlas-on-end-of-life-care>. Access in: 11 dec. 2012.

Recebido em: 28/09/2020

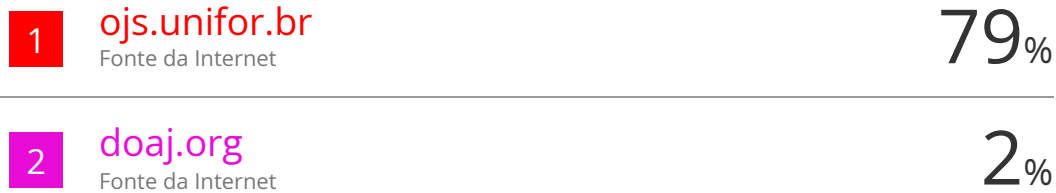
Aceito em: 08/11/2021

f_death_in_search_of_autonomy_and_dignity_at_the_end_of_...

RELATÓRIO DE ORIGINALIDADE



FONTES PRIMÁRIAS



Excluir citações

Em

Excluir

Desligado

Excluir bibliografia

Em

correspondências