Daniela Zilio Riva Sobrado de Freitas

## BODY AND IDENTITY:.. (RE) DEFINITION OF DECISION-MAKING AUTONOMY

IN THE CONSTRUCTION OF THE RIGHT TO OWN BODY



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A revisão linguística é de responsabilidade dos autores.

Daniele Cristine Beuron

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# BODY AND IDENTITY: (RE) DEFINITION OF DECISIONMAKING AUTONOMY IN THE CONSTRUCTION OF THE RIGHT TO ONES OWN BODY

It is undoubtedly very important, nowadays, to publish this collection of texts, focusing on the very personal right to one's own body, in a proposal for bodily self-determination and construction of personal identity, especially at times when we observe an unprecedented social polarization and a great intolerance towards individual differences.

Body and identity go together when it comes to formulating one's own choices, always anchored in respect for the differences that give each one uniqueness and that are presented in their own body, from a physical, mental point of view, or in the intersubjective relationships that each person builds and designs in society.

In this sense, the sharing of experiences and knowledge, in a democratic context of Freedom of Expression and the Right to Information, establishes the bases for the construction of personal convictions and enable choices related to the trajectory of life and the construction of individual identity, in a continuous movement of the pursuit of happiness and personal fulfillment.

Living and dying, according to their own beliefs and convictions, presupposes a (re) definition of Decisional Autonomy concerning one's own body and life and implies a right, not only on the integrality of existence, opposed to the State but above all an update of this autonomy, as a right to

be achieved, with the intermediation of public policies mediated by the State, especially for cases of personal vulnerability.

Therefore, this book seeks to contribute, through eight important texts, to the (re)definition of decision-making autonomy as it is believed it should be envisioned.

The first text, entitled "From private autonomy to decisional autonomy: analyzing the concept and its historical transformation", is therefore concerned with historically considering, from a legal and philosophical point of view, the concept of autonomy until its current understanding of decision-making autonomy.

The second text, entitled "The decisional autonomy and the right to bodily self-determination in personal decisions: a necessary discussion", intends to allocate the so-called decision-making autonomy as a substitute for personal choices that are located in each individual's zone of intimacy.

Next, the third text, entitled "Decision-making autonomy in the defense for the right to die with dignity", is concerned with relating decision-making autonomy to an important decision of personal nature, that is, the decision for the best moment and the best way of dying, with self-dignity.

The fourth text of the collection entitled "The autonomy of the will and the right to death with dignity", sequentially to the objective of the previous text, follows the explanation of autonomy as the possibility that it is the foundation for the achievement of the right to die with self-dignity.

The fifth text, entitled "Personality rights in the search for the dignity of living and dying: the right to death (dignified) as a corollary of the right to life (dignified)", intends to list the rights of the personality as supporting the decision-making autonomy in the search for the right to die with dignity.

Furthermore, from the perspective of the right to die with personal dignity, follows the sixth text, entitled "From dysthanasia to euthanasia:

following the dignity of living and dying". The sixth text intends to investigate the dilemmas faced in the dying process of the terminally ill patient, from the analysis of dysthanasia, or therapeutic obstinacy, to euthanasia, or anticipation of death, gathering the intricacies that circumscribe the terminality of life.

The seventh text, entitled "The right to a dignified death based on the analysis of the decision of the Complaint of Non-Compliance with the Fundamental Precept No. 54", follows the investigation of decision-making autonomy concerning dignified death this time using the arguments explained as a parameter for analysis in the decision of the Allegation of Non-compliance with Fundamental Precept No. 54, judged by the Federal Supreme Court.

Finally, the eighth and last text, entitled "The decision-making autonomy in the concrete plan: case study involving the search for the right to a dignified death around the world", like the previous one, leaves the purely theoretical plan. This time, the objective is to investigate concrete cases of the search for the right to a dignified death in the most diverse contexts, countries, and modes of achievement.

We hope that the collection will provide readers with new perspectives of pondering regarding decisions arising from the construction of the right to one's own body and personal identity, just as the writing of the texts did with us.

Excellent reading.

Spring 2021

Daniela Zilio
Riva Sobrado de Freitas

## CORPO E IDENTIDADE: (RE) DEFINIÇÃO DA AUTONOMIA DECISÓRIA NA CONSTRUÇÃO DO DIREITO AO PRÓPRIO CORPO

É sem dúvida bastante importante, nos dias atuais, a publicação desta coletânea de textos, com enfoque no direito personalíssimo ao próprio corpo, numa proposta de autodeterminação corporal e construção da identidade pessoal, especialmente em momentos em que observamos uma polarização social sem precedentes, e uma grande intolerância em relação às diferenças individuais.

Corpo e identidade caminham juntos, quando se trata de formular as próprias escolhas, sempre ancoradas no respeito às diferenças que conferem singularidade a cada um e que se apresentam no próprio corpo, sob ponto de vista físico, mental ou nas relações intersubjetivas que cada pessoa constrói e projeta em sociedade.

Nesse sentido, a partilha de experiências e conhecimentos, num contexto democrático de Liberdade de Expressão e do Direito à Informação estabelecem as bases para a construção das convicções pessoais e possibilitam escolhas relativas à trajetória de vida e à construção da identidade individual, num movimento contínuo de busca da felicidade e da realização pessoal.

Viver e morrer, consoante suas próprias crenças e convicções pressupõe uma (re)definição de uma Autonomia Decisória em relação ao próprio corpo e à própria vida e implica num direito, não apenas sobre a integralidade da existência, oponível ao Estado, mas sobretudo uma atualização dessa autonomia, enquanto um direito a ser alcançado, com a intermediação de

políticas públicas mediadas pelo Estado, especialmente para os casos de vulnerabilidade pessoal.

Sendo assim, o presente livro busca contribuir, por meio de oito importantes textos, para a (re)definição da autonomia decisória tal qual se acredita que ela deva ser vislumbrada.

O primeiro texto, intitulado "From private autonomy to decisional autonomy: analyzing the concept and its historical transformation", assim, preocupa-se justamente em ponderar historicamente, do ponto de vista jurídico e filosófico, o conceito de autonomia, até a sua hodierna compreensão de autonomia decisória.

Já o segundo texto, intitulado "The decisional autonomy and the right to corporal self-determination in personal decisions: a necessary discussion", pretende alocar denominada autonomia decisória enquanto supedâneo para escolhas de caráter pessoal e que se situam na zona de intimidade de cada indivíduo.

Na sequência, o terceiro texto, intitulado "Decision-making autonomy in the defense for the right to die with dignity", preocupa-se em relacionar a autonomia decisória em uma importante decisão de cunho pessoal, qual seja, a decisão pelo melhor momento e a melhor forma de morrer, com dignidade pessoal.

O quarto texto da coletânea, intitulado "The autonomy of the will and the right to death with dignity", sequencialmente ao objetivo do texto anterior, segue na explicação da autonomia quanto à possibilidade de que seja ela o alicerce para a consecução do direito de morrer com dignidade pessoal.

O quinto texto, intitulado "Personality rights in the search for the dignity of living and dying: the right to death (dignified) as a corollary of the right to life (dignified)", tem por intuito elencar os direitos da personalidade

como coadjuvantes à autonomia decisória na busca pelo direito de morrer com dignidade.

Ademais, na perspectiva do direito de morrer com dignidade pessoal, segue o sexto texto, intitulado "From dysthanasia to euthanasia: reflecting the dignity of living and dying". Este pretende investigar os dilemas enfrentados no processo de morte do paciente terminal, desde a análise da distanásia, ou obstinação terapêutica, até a eutanásia, ou antecipação da morte, amealhando os meandros que circunscrevem a terminalidade da vida.

O sétimo texto, intitulado "The right to a dignified death based on the analysis of the decision of the Complaint of Non-Compliance with the Fundamental Precept No. 54", segue na investigação da autonomia decisória em relação à morte digna, desta vez utilizando como parâmetro de análise os argumentos explanados na decisão da Arguição de Descumprimento de Preceito Fundamental n. 54, julgada pelo Supremo Tribunal Federal.

Por fim, o oitavo e último texto, intitulado "The decision-making autonomy in the concrete plan: case study involving the search for the right to a dignified death around the world", tal qual o anterior, sai do plano unicamente teórico. Dessa vez, o objetivo é averiguar casos concretos de busca pelo direito à morte digna nos mais diversos contextos, países e modos de realização.

Esperamos que a coletânea proporcione aos leitores novas perspectivas de ponderação no que se relaciona às decisões emanadas da construção do direito ao próprio corpo e da identidade pessoal, assim como a confecção dos textos fez conosco.

Excelente leitura.
Primavera de 2021
Daniela Zilio
Riva Sobrado de Freitas

# FROM PRIVATE AUTONOMY TO DECISIONAL AUTONOMY: ANALYZING THE CONCEPT AND ITS HISTORICAL TRANSFORMATION

## **ABSTRACT**

This article intends to investigate autonomy, from the legal and philosophical points of view, tracing an observation path that goes from the emergence of the idea of freedom, through private autonomy (and autonomy of the will), to the analysis of a new conception theme, configured in decision-making autonomy. The issue is the question about what autonomy is and how its constitution and historical transformation took place until its current appearance. To this end, a qualitative exploratory-explanatory bibliographic research was carried out using the deductive method. Regarding the results achieved with the study, it is argued that, from a legal perspective, the relevance of the theme called autonomy is unquestionable as a point of support for the defense of several rights and situations. The conclusion reached is that autonomy is not a tight concept or a stagnant prerogative, but it constitutes an important right and an ideal that permeates several philosophical debates. This theme sought to clarify what is being dealt with when invoking autonomy in the legal and philosophical spheres.

Keywords: freedom; private autonomy; autonomy of will; decisional autonomy; privacy.

## 1 INTRODUCTION

The main subject of this study is the analysis of autonomy in its various biases. Weighted from the point of view of the most critical, autonomy is not

a concept of a single meaning, nor does it claim to be, either in philosophy or in the law and not in the opinion of common sense. Despite this, its understanding has always been sought, from ancient times to the present, whether it is treated under the proper nomenclature of autonomy or it is called freedom, both being synonymous, or whether any possible difference is sought between the terms. It is clarified, opportunely, that the present research works with the philosophical aspect according to which freedom and autonomy are not divergent terms, but that they complement each other, with autonomy being nothing more than the expression of freedom to claim.

The justification for carrying out the study focuses on the relevance presented by it from the legal point of view, since autonomy is considered as a foundation for the defense of a series of subjects, from negotiation, to contractual, to existential. Philosophically speaking, as we know, the relevance is no less. Therefore, knowing what it is about when invoking autonomy is essential, and therein lies the contribution of the present study.

The problem of the study is based on the questioning concerning what autonomy is and how its constitution and historical transformation took place until its look nowadays.

The objective is, in general, to study autonomy from a theoretical perspective, from a legal and philosophical point of view, tracing a way of observing the theme. Specifically, to consider freedom and its ideals emanating from the 18th century, moving towards autonomy (private and will), and, finally, to verify the innovative concept of decision-making autonomy, also known as decision-making privacy.

To this end, the study will be systematized so that, at first, it will start with a historical approach about freedom, so that one can glimpse autonomy, in its biases, primarily concerning the concepts of "Private autonomy" and "autonomy of the will", and, finally, presenting the so-called decision-making autonomy, as a new approach to the theme.

As regards specifically the methodological aspect, the research is based on technical, rational, and systematic procedures, with the purpose of a scientific basis, providing logical foundations for the investigation. Finally, it is a qualitative exploratory-explanatory bibliographic collection research, in which the deductive method is used and in which the intention is to explore and describe the topic in question, revealing the possible solutions for the debate presented, without, however, exhausting the theme.

## 2 FREEDOM: INTRODUCTORY HISTORICAL ASPECTS

Describing freedom is perhaps one of the most difficult tasks for any individual. In science, this is no different and, so much so, there are countless meanings attributed to that word. Alexy (2015) even emphasized that the concept of freedom is one of the most fundamental practical concepts, but, at the same time, one of the least clear.

It is necessary to keep in mind that perhaps there is a certain subjectivism when it comes to freedom in general terms it is a condition for human fulfillment and needs, as a consequence, to be considered. Historically, its space of study has always been prominent.

The struggle for freedom is a mark of the human being. As a rule, it seeks to be free and not to be bound by bonds, whether by the State or by society and, likewise, it seeks to make choices, in a field of decidability, bearing the responsibilities of the consequences of its decisions. Although for many, complete freedom is a utopia, the fact is that one cannot speak of human rights without mentioning freedom.

Certainly, freedom emerged as the ideal of the revolutionary movements of the 18th century. Bauman (2014) states that freedom as the ability of self-government, before "being left alone" by the government, was a dream of the revolutionary movements that guided the Western world

in modern history. Thus, the French Revolution (1789) aimed to transform the "Third State" (the majority of the population, who was denied a real influence on the execution of national affairs) into a free decision-making force for all matters of public interest. Likewise, the founders of the American Revolution sought in their Declaration of Independence the guarantee of a space in which freedom could appear (freedom understood as a full right and universal participation in public affairs). It can be seen, then, that the longing for freedom that pervades the right not to be disturbed by public affairs, being unrestricted and exercised right to manage them, is not new, having accompanied modern societies since the beginning.

Freedom can be conceived as the flag raised by liberalism, as the supreme good of man, according to Wolkmer (1995).

It is considered that, according to Norberto Bobbio, when it comes to political language, there are two means of freedom or two ways of understanding the term. Bobbio (2000) states that the term now means the ability to perform certain actions or not without the impediment of other people or society, or even the State's power. Otherwise, it means that power does not obey rules other than those imposed by the individual. The author attributed the first definition of freedom to classical liberal doctrine, for which to be free means to be in a field of action, not controlled by the State. As for the second definition, for the author, it refers to that employed by democratic doctrine, for which being free does not denote the non-existence of laws but the creation of each human being of laws for themself. Therefore, a liberal would be one that seeks to expand the field of unrestricted actions, as a liberal state is one in which the least possible interference from public power, while a democrat would be one that seeks to increase the number of regulated actions through self-regulation processes, and a democratic state is one in which there are more self-government bodies.

For Bobbio (2000), however, the difference emanating from the possible two uses of the term freedom, in legal and political language, should not leave behind that both may have a common meaning, supported precisely in self-determination, that is, the field of the allowed is precisely that in which each one acts without any external coercion, determined not by others, but by oneself. Likewise, reiterating that a person or a group does not obey laws other than those imposed on themselves, meaning that person or that group determines themself. Thus, it is perceived that freedom as the absence of bonds coincides with freedom as self-determination.

In fact, according to the author, Benjamin Constant understood exactly the difference between the types of freedom when he explained the "freedom of the ancients" and the "freedom of the moderns". The first would relate to the democratic conception, and the second, to the liberal conception.

Benjamin Constant sought still in the year 1819, to distinguish, conceptualizing them, two forms of freedom, namely: freedom whose exercise would be dear to the ancient peoples; and freedom whose use would be useful to modern nations. According to the author, the confusion between those two types of freedom was, during known times of the revolution, the cause of innumerable evils.

Thus, modern freedom would be the right to express opinions, to discuss interests, to choose work and the way to exercise, and, finally, the right to influence government administration, whether through the appointment of officials or representations, claims, among other things, that is, a freedom that comes close to the today's concept for individual freedom.

The freedom of the ancients, according to him, consisted of exercising collectively and directly various parts of the entire sovereignty, deliberating in public places, and voting on the laws. However, compatible with this freedom would be the complete submission of the individual to the authority of the whole. All private actions were subject to surveillance. It seems that

individual freedom was mitigated, as even when it came to religion, it was not respected. Even in domestic relations, there was an intervention. The laws regulated customs, and everything was dependent on them. Thus, there was nothing that the law did not regulate.

Furthermore, individual independence is the first of modern needs, and, as a result, should not be sacrificed for the establishment of political freedom, as advocated by Benjamin Constant. Therefore, none of the numerous institutions that in the ancient republics prevented individual freedom, can be accepted in modern times, according to the author.

Benjamin Constant reiterates that individual freedom is the real modern freedom. Likewise, political freedom is its guarantee, being indispensable. However, asking present-day people to sacrifice, as in the past, their total individual freedom to political freedom is the inevitable way of getting them away from the first. Consequently, once this is done, the second will not be long from being snatched from them.

The freedom of the moderns, then, can be understood as the negative freedom of nonintervention. This negative understanding of freedom, according to Meireles (2009), is nothing new. The affirmation of the individual legal freedom, in this way, was decisive for the scope of the role that the will found in private law through the individualist and liberal post-French revolution philosophy in the 18th and 19th centuries, by the principle of the autonomy of the will.

Moreover, Freitas and Pezzella (2013) point out that one of the first aspirations in modernity, in the 18th century, regarding human dignity, was the affirmation of freedom as an essential value to the human condition, being characterized as space without interference from third parties, guaranteeing to anyone the achievement of their own goals without the duty of obedience to another person.

As they mention, the awareness of freedom as a power of selfdetermination essential to the dignity of the human being is contemporary with the liberal ideological conceptions of the 18th century, corrupted by the affirmation of the bourgeoisie against the absolutism of the monarchy of the time.

However, in the understanding of Freitas and Pezzella (2013), although corrupted in their origins, in the eighteenth century, from the ideological connections of the liberal paradigm, freedom remains a right of choice until today, changing with treatment techniques implemented by contemporary states. The liberal model is characterized by the predominantly negative tutelage and the Social State by the mixed treatment technique: restrictive (negative) and socially protective, striving to make the exercise of freedoms compatible with the community's needs.

Therefore, the characteristics of non-interference already described dress in the liberal conception of freedom, as they expose. On the other hand, for the Social State, whose legitimacy is based on the commitment to harmonize social dissonances, it is not enough to guarantee the self-determination power limited by law, as a consequence of general consent, that is, there is an imperative that the enjoyment of freedom is in line with the interests of the community or such a commitment will not be socially effective. Freitas and Pezzella (2013) observe compatibility between formal equality and the treatment of freedom in liberal ideology and, on the other side, the compatibility between material equality and the recognition of social imbalances, with the treatment techniques given to freedom by the Social State. With this, the authors conclude the emergence of new content for human dignity, where the expectations to be met relate to other values as a way of guaranteeing justice. In addition to freedoms, social rights were included, in the pursuit of contemplating the least favored sectors of society.

In the liberal state, then, there are two connotations concerning freedom: the feature of denial of coercion or intervention; and the possibility of submitting only to standards to which individuals, directly or through representatives, have consented. In the Social State, in addition to the characteristics mentioned, there are restrictions to the enjoyment of self-determination, such as the social function of property, in addition to the realization of police power, conditioning freedoms in general, according to Freitas and Pezzella (2013).

The authors, moreover, conclude that freedom is a choice right, exercised in a given situation, circumstance, or social space, where the person or a social segment (in the case of collective freedom) fully exercises its self-determination. At another point, they conclude that freedom is limited, exclusively by legislative activity, in the liberal ideology, with the enumeration of illicit conduct and, in the Social State, with other restrictions besides those of the Liberal State, taking into account social needs.

With a brief glimpse of freedom from a historical perspective, we then proceed to the specific verification of autonomy, as well as the famous concepts: private autonomy and autonomy of the will.

## **3 AUTONOMY: TERMINOLOGICAL ANALYSIS**

Etymologically, Beauchamp and Childress (2013) explain that derived from the Greek *autos* (proper) and *nomos* (rule, government, or law), the word autonomy was used in the foreground for the reference regarding the self-management or self-government of Greek independent city-states. Since then, it has been extended to individuals and has gained different meanings, such as the rights to freedom and privacy, individual choice, freedom of will, the driver of one behavior, and belonging to oneself. Therefore, they reiterate that autonomy cannot be considered a univocal concept, neither in

the common language nor in the current philosophy, so it is necessary to refine it based on specific objectives.

Rodrigues Junior (2004) also points out that, both, in dictionaries and popular language, autonomy transcends the meanings of independence, freedom, self-regulation of conduct, and self-government. In modern and postmodern times, the meanings explained are, as a rule, opposed to regimes, in which the exercise of self-government encounters barriers in a particular ideal of absolute extrinsic power. According to him, this tension has been clear since classical antiquity.

Still, concerning the historical transformation of the term, autonomy, weighted in a nebulous way according to the author, in the sphere of self-government, self-determination, or freedom of self-conduct, permeated the times when humanism stood out and the consequent valorization of what is proper to men.

Furthermore, after a brief explanation of Christianity - the church - and the exaltation of the free will, which, according to him, already appeared, in a rudimentary way, giving an individual character to human beings through some thinkers of the time, Rodrigues Junior (2004) links the idea of the development of rationalism and liberalism with the question of autonomy.

The author mentions that the development of capitalism demanded new paradigms influenced by an intellectual production that, under the still Catholic mantle of the Renaissance, emerges after the Reformation and takes on a prism of contesting the church, and, secondly, the Absolute State. Liberalism, on the other hand, sought to reconcile formal freedom and security as the foundation of private relations. Instead of status, what matters at the moment is the contract. Thus, the will was the source of rights, and the contract the form of externalization. It is in this space, then, that the autonomy of the will is qualified. An attempt was made to distinguish a

specific field of realization of the will, the space of intersubjective relations of a non-public nature.

Autonomy, consequently and finally, starts to play a notorious role in the legal model of the modern West, mainly in the 18th and 19th centuries, according to Rodrigues Junior (2004).

What can be determined, with this, is that, despite autonomy etymologically representing the government of itself, there is a whole historical construction that allows its modern understanding, which reveals that the concept is not tight, nor does it represent a static and immutable prerogative.

Given this, autonomy receives different conceptions, being weighted in different ways. The term is followed, in the legal sphere, most of the time, by other terms such as "private" and "will". The relationship between private autonomy and the autonomy of the will is constantly raised and deserves its own space for analysis in the current study.

## 3.1 WEIGHTING CONCEPTS: PRIVATE AUTONOMY AND AUTONOMY OF WILL

In fact, when dealing with the nomenclature "autonomy", in the legal scope, two expressions usually emerge, private autonomy and the autonomy of the will. Such expressions are sometimes taken as synonyms and seldom considered entirely different, depending on the doctrinal current in which their explanation is defined.

Moreover, this is what can be extracted from the teachings of Steinmetz (2004). According to him, for some authors, private autonomy and the autonomy of the will are treated as synonyms. Thus, private autonomy would have two main bases: the first related to existential freedoms, and the second linked to contractual freedom and legal business.

Pinto (1999) takes the two expressions as synonymous when he explains that the autonomy of the will - or private autonomy - is the power recognized by individuals to self-regulate their interests, to self-govern their legal sphere (set of legal relations in which an individual is a holder). Such autonomy (or both) means, then, for the author, that individuals have the prerogative to, in the domain of their coexistence with other subjects, constitute the ordering of the respective legal relations.

To other authors, however, the autonomy of the will, despite having similarities, is not to be confused with private autonomy since there is a significant difference between the two highlighted by the focus of the phenomena in the perspective of legal nomogenesis. Thus, the autonomy of the will would have a more subjective, psychological connotation, whereas the private autonomy would mark the power of the will in an objective way, more, so to speak, concrete and real, as collected in Amaral Neto (1989).

Meireles (2009) agrees with this understanding by exposing that the autonomy of the will reveals the will in itself, in its most psychological sense. The primary function of the autonomy of the will was to guarantee the individual's own will since it was considered the only source of mandatory effects. Thus, the principle was established as the legal basis for a liberal economic policy that guaranteed people's will the principal role in legal relations differently, private autonomy would have a more objective connotation, a consequence of the manifestation of that same will being, consequently, a source of juridical effects.

Therefore, "private autonomy" is an extremely widespread expression in terms of private law, being used as a point of support in the most diverse situations, from negotiation to existential ones. According to Meireles (2009), private autonomy means self-regulation of interests, whether patrimonial or non-patrimonial.

In turn, Steinmetz (2004) considers that it is the fundamental principle of private law, especially when it comes to civil law. He defines the term as the power granted by the legal order to individuals so that they, in a free and sovereign way, can self-regulate their interests. In this way, private autonomy would manifest itself as the power of self-determination and self-linkage of private individuals, and therefore, in their exercise, they would be legislators of their interests, creating rights or duties.

Prata (1982) explains private autonomy from a historical perspective and, it seems, relates it especially to legal businesses. In his teachings, he clarifies that there is an unmistakable relationship between private autonomy and the concepts of legal subject and property. According to him, however, all those concepts are not universal but belong to the domain of relationships between owners. The attribution of legal personality and negotiating capacity is linked to the emergence of private ownership and property rights. The same is true when it is recognized to the employee ownership of their workforce, and from there, it is a recognized legal personality and negotiating capacity so that they can enter into a contract by which the connection between the worker and means of production mediates.

Also, to Prata (1982), the implantation of the capitalist mode of production brought the need to universalize these concepts to the extent that everyone, from then on, becomes a legal subject, having, in the same way, negotiating capacity. However, the need is imposed in the face of the reality previously experienced, where the worker was linked to the land and the feudal lord. Hence, from a philosophical point of view, overcoming this situation defines the affirmation of people's freedom, their liberation from the bonds that unite them to the land and their masters.

At that moment, according to the author, the concept of private autonomy gains autonomous and imperative content, and it is precisely this content that will invest the very notion of legal business, in which it is no longer taken in the perspective of an instrument for the exchange of goods, to highlight its character of realizing economic freedom. In this sense, the business is considered the person's freedom affirmation, being the legal effect of free will. Therefore, it proposes that the legal concept of private autonomy has its emergence and configuration linked to historical conditions, mainly from the passage of feudalism and capitalism, constituting at the same time an instrument and a consequence of the economic and social transformation that operated.

Under this bias, then, private autonomy, or business freedom, would be, for Prata (1982), the power recognized by the legal order to man, previously and necessarily qualified as a legal subject, to legalize their activity, carrying out legal business in a free and determining their effects.

In turn, the autonomy of the will, in addition to being a legal concept, is also considered a philosophical concept, given the origin of the expression.

Therefore, according to Rodrigues Junior (2004), in a traditional way, Immanuel Kant is invoked as a precursor to the term "autonomy of the will", based on his work "Metaphysical foundation of morals". Immanuel Kant understood freedom as the autonomy of the will. So much so that the author explained that morality exists in the relationship of actions with the autonomy of the will, with the ability of the rational being to legislate and submit to the legislated law, being treated as an end, and never simply as a means.

Thus, Kant (2003) explained that the autonomy of the will would be the constitution of the will, where it is for itself its law, in such a way that the principle of autonomy is summarized in choosing a way so that the maxims of the choice of one's desire are, at the same time, included as a universal law.

As Beauchamp and Childress (2013) explain, for Kant, all people have unconditional value, so that the violation of the person's autonomy would be the same as treating them as a means to achieve the goals of others, which,

for him indeed, it cannot occur, since all individuals are ends in themselves, capable, therefore, of determining their destiny.

Thus, it is considered that, according to Kant (2003), autonomy, and human dignity itself, have always been close figures, being that the foundation of this and all rational nature.

However, the Kantian doctrine is not immune to criticism. The author, of jusnaturalist influence, conceived the autonomy of the will as such. Starting from the jusnaturalist assumption, he could not then consider a process of transformation of the concept or even the cultural, historical, and temporal differences that, consequently, imply a paradigm shift concerning the scope and approach of the theme.

In philosophical terms, the expression is attributed, and with all the property, to Immanuel Kant. On the other hand, in legal terms, its relevance is no less, nor could it be; beyond the theoretical-philosophical field, legal practice depends on the precepts emanating from the principle.

Historically, the institute was taken as a representation of the will of each subject, a will adopted as a source of compulsory rights.

Seeking to make the concept explicit, Amaral Neto (1989) clarifies that the field of freedom provided by the person in private law, or their right to be governed by the laws themselves, is called autonomy. From there, he clarifies what, for him, is the autonomy of the will, in legal terms. The autonomy of the will, then, is the principle of private law according to which people can practice a legal act, attributing to this act the content, the form, and the effects. Its sphere of application, by excellence, is a mandatory law, where people can dispose as they see fit unless there is a relevant provision to the contrary. Note that the concept is similar to that related to private autonomy, and it is precisely for this reason that the author makes a point of differentiating them at this moment because, for him, both are not confused. He reports

that when the reference is specific to the individual's power to establish the legal rules of their behavior, he speaks of private autonomy, to the detriment of autonomy of the will. The autonomy of the will manifests the freedom of each person, being a more, so to speak, psychological concept, and private autonomy, the power to create its legal norms as long as within legal limits.

Finally, although formally relevant to the definition of the exposed concepts (private autonomy and autonomy of the will) and their differentiation - or analysis of both as synonyms, if conceived - contemporary doctrine has been dedicating a truly important study space to a new way of analyzing the theme, which therefore proposes a new nomenclature. Such analysis does not start from liberal, individualistic, nor communitarian ideals, but it brings up a different form of approach. It is the decision autonomy.

## 4 RETHINKING THE TERM: THE REDISCRIPTION OF THE RIGHT TO PERSONAL PRIVACY IN THE CONSTRUCTION OF DECISIONAL AUTONOMY

Initially, it should be noted that, when the doctrine refers to the autonomy of each individual, in being able to make their choices based on their values and their life experiences, criticisms are commonly raised regarding a supposedly too individualistic view, along with the liberal lines, displaced individual, uprooted from the social whole. Such criticism, will be continued later, must be conceived that the decision-making autonomy that we seek to deal with is not based on that assumption, since it transcends the concept of the struggle for the non-interference of others or the State, in the choice of every human being. Therefore, the aim is to contemplate the autonomy that allows the construction of one's own identity in search of personal dignity.

In this way, the analysis that will make the study presupposes the existence of a decision autonomy that, as already mentioned, is not based

on already famous ideological conceptions, whatever they may be, but rather brings a new type of ideological and theoretical approach about the topic.

Asserted decision-making autonomy is precisely that which gives weapons to the construction of each individuals identity, as it allows the externalization of personal desires in making important decisions of an eminently personal nature (hence the reason why it is also known for decision-making privacy) and contributes to the empowerment of the person about himself, about his body, and his decisions. Jean L. Cohen (2012) conceives that such autonomy involves what she calls "zone of intimacy". To her, that is an area of real conflicts in which the very principle of individual right to privacy is contested.

Thus, to understand decision-making autonomy, it is necessary to understand the right that serves as a foundation, that is, the "right to personal privacy". This right has two important dimensions, according to Cohen (2012).

The first of those dimensions do not seem to be controversial. It consists of the right to be "left in peace", which is the right not to suffer intrusion or surveillance without there being, at least, a just reason. Regarding this dimension, Freitas and Pezzella (2013) reiterate that it is not a question of recognizing yet another individual right, in liberal terms, but of protecting the person's intimacy, which precisely makes them unique and identifies them among all the rest.

The second dimension, which is more controversial, deals with "decision-making privacy", as Freitas and Pezzella (2013) call it. It is the right not to be subjected to undue control, inclusively concerning possible regulations by other people, as ponders Cohen (2012).

Thus, the first dimension refers to the possession and dissemination of information, and the second, primarily to decision-making autonomy related

to the intimate aspects of each individual, including even private availability, according to Cohen (2012).

This dimension, therefore, reveals the decision-making autonomy that it aims to consider. And it is concerning this dimension that censorship is formed with greater acidity.

As previously exposed, the criticisms related to decision-making autonomy almost always raise the question concerning possible excessive individualism, or the lack of concern for the social, the collective, arising from the struggle for the preservation of the individual rights of freedom.

In other words, as revealed by Freitas and Pezzella (2013), taking into account the second dimension presented, the main criticisms about individual rights in general, and specifically concerning privacy rights, refer to the liberal model society/State, which, in supposition, would gain strength for the protection of privacy as "decision-making autonomy".

It does not seem to be the case. Cohen (2012) wisely opposes the opinions that he believes to be decisions based on decision autonomy as decisions that take into account a collection of separate, isolated individuals. He reports that the principle that the individual privacy rights, which protect decision-making autonomy, are compatible with the recognition of the intersubjective character belonging to the processes of formation of personal identity and awareness of the historical and contextual sources of values.

Thus, according to Freitas and Pezzella (2013), the right to privacy needs to be taken up from a different perspective, especially in its dimension of decision-making autonomy. According to the authors, it designates the individual as the center of their decision-making process and does not determine an ethical or ideological choice to be followed, but only a sphere of self-determination in which each person can and must perform their identity

concretely. Individual choices can be made for their reasons, as Cohen (2012) designates, and even there is no need for them to be justified to other people.

In this same north, personal privacy rights ensure areas of decision-making autonomy for all individuals, in no way generating a voluntarist conception of the individual. Thus, when the question of autonomy appears in Cortes' decisions, there is no need to impose on them a voluntarist ideal of person. Assigning decision-making autonomy to an individual militates against state paternalism.

Freitas and Pezzella (2013) also comment on the recurring criticism related to the perception that decision-making autonomy, when it protects the power of self-determination, would encourage the individual to uproot themself, thus causing them to break with the community values, thus breaking the bonds of solidarity that surround it. For the authors, the idealized collectivity as a sum of people in which each defends nothing but their interests translates into the denial of the possibility of the existence of a social whole, and if so, the only possible identity among its members, as they explain, would be the vocation to possess, which is intended to be inherent in "human nature".

What happens is that this is not the case when talking about decision autonomy, according to Cohen (2012). Freitas and Pezzella (2013) also make this very clear. For the authors, it does not seem appropriate to subordinate the Right to Privacy, specifically in the decision-making dimension, to the connotation of an uprooted individual since what them would truly seek would be the protection of the personal autonomy core in the face of, as defined by them as "community norms" that, in certain circumstances, could be abusive concerning personal decision-making autonomy, and, likewise, in the face of the majority's own will, often disrespectful to diversity.

Therefore, privacy rights ensure, according to Cohen (2012), everybody preconditions to develop integral identities that they can evaluate as to their

own. On the other hand, because they equally guarantee legal personality and decision-making autonomy to all, those rights protect the demand of each individual, regardless of whether theyr are "different" from the others. They also protect the personal dimensions of the individual's life in the face of undue interference and safeguard the processes of self-development and self-realization involved in the formation of identity.

However, the exercise of the explained decision autonomy presupposes the right to information. It is explained: for the subject to be able to make choices based on their decision autonomy, they must be very well informed about the paths to be taken, as well as the consequences of making each decision.

In this north is the understanding of Beauchamp and Childress (2013), who clarify that respect for the autonomous agent implies the recognition of their right to have opinions, make choices, and act based on personal beliefs. The explained respect involves action and requires, in the same way, more than obligations of nonintervention in people's decisions, since it includes commitments to sustain people's capacities to choose autonomously, reducing fears and other issues that may disadvantage the exercise of autonomy. That implies on enabling people to act autonomously, informing them, therefore, and opposing disrespect, which involves attitudes and actions that ignore, insult, or degrade the autonomy of others and, consequently, deny the existence of minimum equality between people.

Starting, then, autonomy from a positive perspective of freedom, it would not be for the State to interfere in the strictly personal decisions of each individual, but rather it would inform and discipline the sensible use of personal autonomy to protect privacy decision-making. In other words, the State cannot demand that people reveal the reasons for acting in a domain in which they have the right to act for their reasons according to Cohen

(2012), but it has a duty of information, so the choices are made safely and responsibly.

In the same way and especially because it is relevant, in matters of a strictly personal nature, the decision-making autonomy explained, presupposes the control of each person over their own body to safeguard their dignity. Thus, in the exercise of decision-making autonomy, each individual deserves to take possession of their own body, viewed in a global and integrated way, in the face of opinions from society, the community in which they live, and even the State itself, insofar as, if the individual has the right to decision-making privacy, it is not for the State to interfere in such an invasive way in their privacy, but to guarantee conditions for the regulated exercise of autonomy, acting in this aspect, in a positive way.

## **5 CONCLUSION**

The theme on which the study in vogue is based is extremely relevant, from both the philosophical and legal points of view. It was intended to carry out a general approach on the theme, bringing historical aspects that could clarify how autonomy is - or can be - currently conceived.

Initially, we sought to envision autonomy as freedom in a historical perspective since its "appearance" in conceptions from the 18th century. It is important to relate that it is assumed that freedom and autonomy are not separate concepts, as some thinkers may consider, but that portray the same desire and the same need.

Then, starting from the ideal of freedom in which people can selfdetermine without abusive interference by the State and other people, acting with decision-making power, one arrives at the notion of private autonomy, in which the object of expression of this freedom is, in short, the contract (the legal business itself), that is, people, insofar as they are free to determine their laws, in a particular perspective, can agree and stipulate the rules valid for the parties, through contracts.

The autonomy of the will, in turn, in a Kantian philosophical perspective, determines that individuals are ends in themselves, capable of deciding their destiny, and not a means to reach the end of others (evaluating themselves very succinctly the theme). Nowadays, from a legal perspective, the autonomy of will has been related to the autonomy to practice acts with content determined by the individuals themselves.

Thus, the nomenclatures of private autonomy and autonomy of the will (in the legal perspective) can be seen as unambiguous or as concepts that show different results. If so, private autonomy would have a more objective, expressed character, and the autonomy of the will would be more subjective, envisioning the will in its internalized psychological conception.

Furthermore, it is obvious that the liberal ideals of non-intervention contributed to the construction of the autonomy that one has today and to the autonomy that is sought. Despite that, a new form of the theme was presented in the text, detached from an individualist or communitarian conception, which aims to protect the personal identity of each individual by safeguarding their privacy to decide: it is, therefore, the decision-making autonomy.

Decision-making autonomy is, therefore, the prerogative that gives the individual control over one's decisions, removing them from the pressure to adopt the reasons that the rest of the people accept. In that conception, the individual is the center of their decision-making process, acting while being socialized - and sociable - but according to their conceptions in their sphere of intimacy.

It can be concluded with the approach taken, in a tight and unpretentious synthesis, that, despite the human need reflected from the

most remote times, and pleaded especially since the liberal ideals emanating from the 18th century, autonomy is not a concept univocal or tight, nor does it represent a stagnant and immutable prerogative. It evidences a right of unparalleled importance for a long time, and, mainly, nowadays, which serves as a guide for the defense of several other rights, in addition to being a concept that regularly permeates philosophical debates. It, therefore, needs to be continually studied and considered.

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# THE DECISIONAL AUTONOMY AND THE RIGHT TO CORPORAL SELF-DETERMINATION IN PERSONAL DECISIONS: A NECESSARY DISCUSSION

#### **ABSTRACT**

The present paper has as a problem the interrogation of the existence of decisional autonomy and its consideration as a necessary foundation for the realization of one's self-determination over their own body. To solve the questioning it has been made qualitative exploratory-explanatory bibliographical research by using a deductive method. The conclusion obtained is the one which is clear about the existence of a right of exercising the decisional autonomy that provides empowerment to the private decisions, and that, therefore, guards the human being in their identity and personal dignity. As a result of the research, in this way, it is an inherent prerogative to the human being the recognition of their self-understanding, and the established decision-making autonomy is essential in the construction of that right. Keywords: Decision-making autonomy; body self-determination; right to

#### 1 INTRODUCTION

own body.

The body is the means of communication of each and every individual to the external world, and it is through it that all the relationships in which that same individual participates are mediated. The human being's body expresses its way of being, translates its intentions, and makes it possible to coexist among beings. It also participates in the person's identity, insofar as

how they see themself and places themself before the world passes through their body recognition and self-understanding.

Autonomy as existential freedom is also a means that allows the individual to recognize themself as such, insofar as through it, the individual can choose which paths they intend to lead their existence. Thus, it is questioned about the decision autonomy mediating the subject's relationship with the world, through their body, with what in this study is called "body self-determination".

The issue under investigation here, is raised in the following question: what constitutes decision autonomy as a substrate for body self-determination?

Therefore, the objective is to investigate what decision-making autonomy is, notably as a basis for the configuration of the right of body self-determination. Specifically, the objective is to analyze decision-making autonomy after pondering about what the right to one's own body is about and then to study decision-making autonomy as a guide for body self-determination.

To this end, the structure of the article will take place as follows: first, a punctual analysis of decision-making autonomy will be carried out as a pillar of the right to privacy, afterward it will start with the necessary explanation about the right to one's own body, so that finally, it is possible to glimpse, in a third moment, body self-determination as an essential part of decision-making autonomy, investigating some important and difficult questions related to the subject.

The choice of the theme is justified by the prominence of the legal controversy related to it, since the defense of decision-making autonomy, especially concerning body self-determination, carries within it, precisely for the not easy cases faced, certain controversy, and lots of resistance from a

good part of the thinkers and operators of the law, and this is where the importance of pondering over, reflecting and bringing up the debate resides. Furthermore, the discussion of the topic is undoubted at a time when the defense of body integrity is so evident.

Furthermore, the topic has an indisputable relevance precisely for what was reported, and insofar as it supports the analysis of several discussions that have as their birthplace the nucleus that emanates from decision-making autonomy and that carry, often, social, ethical, and moral stigmas for as well as legal, as will be seen in due course.

Methodologically, the research is based on technical, rational, and systematic procedures, which bring a scientific basis and provide logical foundations for the investigation. Still, it is a research of exploratory-explanatory, qualitative bibliographic collection, where the deductive method is used, and the purpose is to explore and describe the subject under consideration, despite not having the intention of exhausting the theme.

# 2 DECISION-MAKING AUTONOMY AND THE RIGHT TO PRIVACY

When it comes to autonomy, theoretical discussions related to private autonomy and its consequences in the legal world almost always emerge. It is thought that it could not be different, even due to the importance of the theme. The negotiating emphasis of the concept and its visualization as a power of self-regulation of conduct takes a prominent place, and this must be the case because there is no doubt about its relevant dimension in the formalization of legal business.

In fact, as Steinmetz (2004) ponders, private autonomy is certainly a constitutional value. Therefore, it must be observed and respected, including under the contractual prism related to it.

Regarding that, its role in private law is certainly extremely relevant, and it is even a fundamental principle, especially concerning civil law, according to the same author.

Nevertheless, the existential perspective linked to autonomy, we dare say, seems to bring even more counterpoints. That is because, when it comes to choices to be made in a field of decidability, despite the questioning or acceptance of the whole, the polemics emanated are clear.

When one reasons the existential perspective of autonomy, one thinks, of course, of private autonomy as a personal bias of action. However, it must be explained here that when mentioning the term decision-making autonomy in this study, it is thought of as a branch of the right to privacy. The investigation will take place under the cloak of the doctrine of privacy arising from American law.

Regarding autonomy in the existential perspective of the theme, although not in the same way as here, in a very punctual way, Barroso and Martel (2010) state that it is the right of each person to choose life projects, without suffering any prejudice, segregation or intolerance, because of what it is or the options they make.

Notably, the expression "autonomy", when added to the expression "will", reveals its very important face glimpsed by Immanuel Kant and his "autonomy of the will". Of course, the word has gained legal connotations over time, but it is also certain that Kant, and the Kantian philosophy itself, emerge with intensity when thinking about such a term. Although it is not precisely autonomy in the Kantian perspective that we seek to deepen here (just as private autonomy is not, in its negotiating prism), we cannot fail to mention the brilliant contributions of the author so that it is possible to understand autonomy the way it can be understood today.

In the same way, it is necessary to relate that autonomy in the existential perspective was raised to one of the four principles of bioethics, therefore, its respect becomes essential when discussing issues related to the theme and, likewise, to the bio-right. Despite all the controversy, it must be said that, according to Beauchamp and Childress (2013), the principle of respect for autonomy presupposes a negative form of analysis, which can be exemplified in the sense that human actions should not be subject to controlling pressure from others. According to the authors, the right of self-determination, the foundation of several rights of autonomy, including confidentiality and privacy, is related to this obligation. Therefore, this principle needs to be specified in specific cases to become a guide for the proper conduct so that the relevant specification will include valid exceptions.

Well then. That said, it is necessary to reflect the autonomy under the bias of the right to privacy, resized, as commented before. Thus, autonomy from the perspective of privacy concerns the possibility that people can make choices and be responsible for them, based on their life path, without having to express justifications or having an external influence on those decisions. The construction of the identity of the being goes through the complexities that are not always easy of the decision-making autonomy, and, certainly, the protection of the individual's dignity of each person is based on respect for that right.

See, if not, what Jean L. Cohen (2012, p. 184-185) notes when explaining the subject of privacy: "the rights of personal privacy [...] do not determine the types of reasons that someone gives for moral or ethical decisions or the reflective processes that inform the decision." Furthermore, adds Cohen (2012, p. 190-191): "[...] one cannot be forced to reveal the personal reasons for these ethical choices or to accept, as their own, the group reasons or judgments." The author works, according to her, apart from

the liberal or communitarian theories, strictly envisioning the privacy that leads to personal dignity, regardless of such views.

In the same sense, Cohen (2012, p. 193, author's emphasis) brings the idea of the individual's empowerment about their identity in the sense that:

In this normative conception of privacy, what is crucial and empowering is the feeling of control over the needs of one's own identity, over access to oneself, over which aspects of oneself will be presented at what time and to whom, together with the capacity to demand or waive demands for access. In effect, it is the sine qua non for someone to understand themself as an independent person - an individual who deserves respect and is capable of establishing consideration. In our society, the new privacy doctrine ensures more than an abstract principle of respect for people as agents of their choices, more than secrecy and loneliness conferring decision-making autonomy over certain personal issues, privacy rights ensure the individual the legal recognition of their "ethical competence" for their selfdefinitions and decisions about which aspects of themself to bring up, at what times and with whom. Thus, privacy rights protect and even help constitute the structure of mutual recognition and social ritual through which someone's identity is recognized, and their individuality is ensured.

The author explains that personal privacy rights ensure that all individuals have decision-making autonomy, in so-called crucial matters, and of a personal nature, without, as stated, the reasons for moral choices or the reflective processes that inform the decision. Of course, as the author points out, what is seen as a crucial personal issue changes over time, and it can certainly be among subjects of intense debate and conflict. For her:

While people do not create the traditions, standards, and norms in which they are initially socialized, to the extent that they become individualized, they invent and reinvent the unity of their lives and their unique identities (naturally, in interactive and communicative processes). They also contribute to reinterpreting and reinventing meanings, norms, traditions, and narratives. Being both constituted and constitutive, the identity of the concrete individual is not just a set of preferences among which it is possible to choose in a way they choose clothing. But it is also not simply the product of community values, social roots, shared traditions, or a set of social roles. All of these elements are open to conflicting interpretations by individuals and subgroups within a given society. Precisely because it

is the task of individuals to develop and express their self-conceptions from (and within) a multiplicity of participations and affiliations, roles and structures, in which they are involved, precisely because they demand recognition for their concrete personalities, their opportunity for self-development and experimental self-presentation requires protection. Such protection provides the individual with a sense of control over their self-definitions, over the self-creative synthesis that only they can conform from their various situations and experiences, in part through communicative interaction with others. (COHEN, 2012, p. 187).

Still, Cohen (2012) argues that concerns about the dimensions of identity are resumed and, in this perspective, argues that privacy rights (in the view of "right to privacy") protect, insofar as they are necessary for that, as he adds with propriety (COHEN, 2012, p. 188): "both action and identity, both self-determination and self-realization, both autonomy and authenticity, without prescribing a specific concept of the person at any level." For the author, the right to personal privacy that guarantees access and decision-making and that guarantees the multiplicity of identities in the face of a possible leveling could have in mind some idea of the "majority's" thinking. For her, despite the voice and participation in democratic public spaces that help to protect the difference, the rightsto individual personal privacy are essential, as they preserve the minimum constitutive preconditions for each individual to have their own identity and ensure, above all, respect for the differences.

It is precisely in this sense that there is a position concerning the non-need of contentment of the majority with the choices that each individual makes, not because it is not important what the whole accepts, but because each person knows about themselves, the peculiarities inherent to them. There is no talk at any time of opposing or overlapping other's ideals, but only of "fighting" for oneself and determining, from there, the paths of each person's existence in their sphere of privacy. About that, Cohen (2012, p. 191, author's emphasis) asserts:

[...] In other words, the right to personal privacy involves precisely the releasing of the obligation to justify one's actions in a discursive process, freeing the need to offer reasons that everyone could jointly accept as their own. To put it another way, privacy as a decision-making autonomy frees the individual from the pressure to adopt, as their own, the reasons that everybody accepts. This telos towards consensus is in force for moral discourse in strict terms and may be an ideal for political decisions supported by state sanctions, but it is not required for existential or ethical choices covered by the rights to personal privacy. In other words, the right to privacy enables someone to choose with whom to seek to justify their ethical decisions, with whom to communicatively rethink conceptions about the good. and, of course, to choose not to discuss certain matters with anyone else. For, concerning personal decisions shielded by the protective cover of decision-making and informational privacy, it does not matter if the decisive reasons for me could also be accepted by someone else. [...]

In the same sense, Warren and Brandeis (1890) determine that the protection of society must come primarily from the recognition of the rights of each individual, recognizing, therefore, each being as a rule, responsible for their acts and omissions. Equally, it is argued in Cohen (2012) that the protection of the right to privacy as decision-making autonomy occurs not for the construction of the well-being of the whole but because it is part of an indisputably central element in the sphere of an individual. Each person's decisions must respect themselves as belonging to themselves, and that is what privacy is meant to embody.

However, as the author notes (COHEN, 2012, p. 197, emphasis added):

[...] I would say that the idea of bodily integrity captures a crucial dimension of our situated identity, but not all of its dimensions. We are also individuals situated in a sense highlighted by communitarians: we develop self-definitions based on culturally available resources in our vital environment; we use our location in a specific set of institutions, relationships, and contexts; we use (often in a creative way) speeches that partly pre-structure what can be said and thought; and, because of all this, we shape our creative contribution to our self-forming processes - our identity. Our relationship with the body, our *embodiment*, is the crucial substrate of our identity, but not the whole. [...] As with the other dimensions of privacy, we need bodily integrity both when interacting with others and outside it.

In this line of thought are the choices or the intimate decisions or, if you prefer to say, located within what is called the "intimacy zone", that is, personal bias decisions concern each person, and it is them who should decide if and with whom to share, and not the whole for them. This is precisely where the empowerment over the body resides in making each of these decisions, and as a necessary presupposition, the right to the body itself.

#### 3 "MY BODY IS ME": THE RIGHT TO MY OWN BODY

The right to the body often permeates the ethical and legal discussions that circumscribe matters that are not always easy to ponder. Whoever defends the right to their own body protects nothing less than themself, since the body of each being is not merely a wrapper of what it is. The body is, therefore, the being, part of its essence, even as a subject of law. It seems clear, then, that the body receives the legal protection that fits the concept of person. What is not always clear is the possibility for each subject to have the empowerment over their body in making some significant decisions, as explained before.

The feeling of empowerment about one's own body accompanies the development of an entire process that culminates in the exaltation of each person's right to be, in fact, autonomous. It is clear that, although this feeling is, in principle, intrinsic to the human being, the detachment of this autonomous thought concerning the right to one's own body was not always (and perhaps not yet) seen with "good eyes" so to speak.

However, regarding the right to the body, Freitas and Pezzella (2013) delineate that, it is part, or inherent, of a right to privacy. In this sense, indeed, it is still loaded with a certain distrust regarding some of its consequences (which will be seen later, at the right time), but, in fact, the existence of this right, in itself, seems to be unchallenged.

Certainly, the discussion on the right to one's own body runs through the idea of personality rights, as reiterated by Freitas and Pezzella (2013), as they reach legal provisions on the body itself and privacy.

Thus, the rights of the personality, present in the Civil Code, between articles 11 and 21 (BRAZIL, 2002), are those intrinsically linked to the concept of human dignity, exposed in the Federal Constitution of 1988 (BRAZIL, 1988), in its article 1, item III, as the foundation of the Federative Republic of Brazil. They are also intended to protect human beings as a person in their characteristics and prerogatives. Surely, the list that appears in such a legal diploma is not exhaustive but merely exemplary, not least because the scope of protection for the person goes far beyond any of the limits established by those articles that are expressly transcribed in the legal text.

Thus, despite the differences in the nomenclature used, according to Bittar (1989), since some authors use the expression "essential rights of the person", some others use "rights to personality or essential rights", "Personal rights", and, also, "very personal rights", it is certain that the most technical and mostly adopted expression by the Brazilian doctrine is: personality rights. The expression is even consecrated in the Brazilian Civil Code.

Thus, although the aforementioned is relevant, it is true that what undoubtedly matters is not exactly the nomenclature used to translate those rights, but, without a doubt, their scope as prerogatives designed to protect the human being as a person.

Therefore, clarifies Amaral (2002) that personality rights are subjective rights that aim to protect the person's essential welfares and values, covering the physical, moral, and intellectual dimensions. Furthermore, the psychic dimension is also under the protective cloak of personality rights.

So, if the rights of the personality include the protection of the human being in their physical, psychological, moral, and intellectual dimensions, the right to one's own body is covered, acting under the aegis of what is an even more established concept (the concept of "personality rights"). Although there has already been a reference to this in the present study, it is necessary to return to the discussion insofar as, and because, the right to one's own body reveals exactly what is sought to exemplify here.

Therefore, it is necessary to refer, according to Chaves (1977), Chaves (1994) and Freitas and Zilio (2016b), that issues related to the body and the right to it have been discussed for some time, although not with the breadth of modern times.

That is because the subjects that demand the return of the subject's gaze towards themself, and their rediscovery as a person, seem to have gained more space nowadays, which, in itself, already shows a significant gain. Pleading the prerogative of having, in practice, a right over one's own body (with the forgiveness of pleonasm) translates into reality what all people, to a greater or lesser degree, seek: precisely the exteriorization of a feeling of freedom, which must, however, be used responsibly.

Thus, as previously mentioned, the individual deserves the right to control their body without having to justify themself to others. On the other hand, but in no way incompatible, the recognition of other people over the control that each individual has over their own body is also important, since, as Cohen (2012) and Eisenstein (1988) relate, without the recognition by other people of someone's autonomous control over their own body, and also over their bodily integrity, with, finally, a recognition of their dignity, the person's image of themselves is impaired, resulting from this damage, the loss of self-confidence and the security necessary to interact healthily with others and demonstrate the feelings and needs they have. It is what Habermas (2010) calls self-understanding, and it certainly goes through the recognition of others, as is also shown in Honneth (1992). Honneth (1992) clearly explains the withdrawal of the person from their right to dispose of

their own body as a form of disrespect, since if this occurs, there is absolutely a loss of recognition of the individual concerning themself.

Having said that, the imperative of a right to one's own body stands out, and from there, the necessity of having decision autonomy over it, so that the individual, as a person, can make certain decisions, which are only of interest to them.

# 4 BODY SELF-DETERMINATION AS THE ESSENCE OF DECISION-MAKING AUTONOMY: SOME ISSUES

The previously stated decision-making autonomy brings together in its concept the idea of protection from eminently intimate decisions and personal content. So much so that Wolff (1950) reports that the feeling of self-determination is paramount to the perception of what it means for someone to be, in fact, a person in the full sense of the word.

Therefore, body self-determination is found on two different bases, that is, as a consequence of its exercise, but before that, as a precondition for it to exist. Despite the apparent paradoxical or dichotomous conclusion, it is thought that this is the relationship between those rights. It is explained: body self-determination can be seen from the decision autonomy, in the sense that it is a logical consequence, since that bases the individual in making intimate and personal decisions, and the decisions related to the body itself are within the concept of intimacy embraced by decision-making autonomy. The premise that the right to the body is presupposed for the actual effectiveness of decision-making autonomy, or its existence, seems to be latent because it is necessary to see that, for the taking of personal decisions, first, the individual in question needs, and can be empowered with their own body so that, with the privacy to decide, they can reflect their autonomy. Determining autonomously on intimate matters reveals, above all, and in a previously debatable reality, the pressing need to take, the being,

the possession of their body, its different dimensions, and, only then, to truly exercise their decision autonomy.

In this argumentative field, it remains clear that the right to one's own body has a special reason of being because the exercise of the claimed autonomy presupposes the individual's control over their body, not because the body is perceived as a negotiable object, but because it is conceived as an essential element for the configuration of the identity of each being, insofar as the individual's body is, in fact, the individual themself: they are not separable things as Eisenstein (1988) argues. Thus, the right to psychophysical integrity, a genuine personality right, further subsidizes the right to choose a dignified and less painful death, solidifying the protection conferred to the individual in its dimensions: physical, psychological, and moral, in the face of the indignity of a suffering-laden survival.

According to Freitas and Zilio (2016b), the right of self-determination over the body is supported by the right to personal identity also inherent to human personality, since the recognition of the person in their identity passes through their recognition in the body dimension, as explained before. The body is, therefore, the vehicle of communication of each human being with the world that is external to them, and the identity of that being is built by analyzing the body as an intrinsic part of its development.

It seems clear, then, that body self-determination goes through the not easy, although necessary, path of body self-understanding considered by Habermas (2010) and already listed in Freitas and Zilio (2016b).

Still, regarding self-determination, Barroso and Martel (2010) explain that it encompasses the prerogative of discerning about the ideals of life and personality development, obviously, with due responsibility in making decisions and intimately, with the consequences arising from them. The authors make explicit the capacity for self-determination described as inherent in what they call dignity as autonomy. Thus, the authors also list the

need for the conditions to be exercised for the exercise of self-determination as a determining aspect (economic, educational, psychophysical conditions), as it is essential, for them, to promote adequate means so that freedom (as they call it), is real, not just rhetoric.

Body self-determination, on the other hand, commonly refers to autonomy concerning the body itself, to the right of empowerment over it for making intimate, personal decisions, which do not always need to be externalized to the whole, although sometimes this whole exercise a kind of control over people, making them believe that the community prevails even in strictly personal matters. As can be seen in Beauchamp and Childress (2013, p. 444), "The principle of respect for autonomy, therefore, includes the right to decide, as far as possible, what will happen to oneself - to one own body, to information about their own lives, their secrets, etc."

In this path, we seek, from now on, to bring up some of those subjects, which perfectly illustrate the exposed, as will be seen.

About body self-determination for the use of tattoos, Freitas and Pezzella (2013) report that tattooing is, therefore, a way of expressing personal and individual aesthetics, which in turn emanates from the exercise of decision-making autonomy over the body itself, or, as it was preferred here to call it, of bodily self-determination. The authors report their concern about the exercise of autonomy over the body concerning tattoos, precisely because these cannot be, in themselves, the limiting reason for accessing, for example, public office positions.

Furthermore, it is true that when it comes to body self-determination as a substrate or basis for the configuration of decisions that culminate in controversial events, as is the case with dignified death (when expressed through euthanasia and assisted suicide), and abortion, the issue takes on significantly greater proportions, due to, presumably, facing life/death decisions.

Thus, although it is not the main purpose of the article to examine each of those issues in detail, it is thought that in the case of "dying with dignity", the exercise of bodily self-determination to choose death in a humanized way, and, perhaps, anticipated, does not translate the option for death to the detriment of life, but the option to live the act of death as the last act of life, in the way, and according to how, all that life was lived, as already exposed in Freitas and Zilio (2016b) and Freitas and Zilio (2016a).

Explain Freitas and Baez (2014) that dying with dignity comes up against a series of paths and, otherwise, there are also numerous paths available for its effectiveness, considering, in both ways, the advanced technology in the medical field today. Barroso and Martel (2010, p. 101) maintain, defending the death that occurred in their time and without, at least, the lack of therapeutic obstinacy, that:

[...] contemporary medicine and technology are capable of transforming the process of dying into a longer and more painful journey than necessary in a fight against nature and the natural cycle of life. At that time, the individual must be able to exercise their autonomy so that death arrives at the right time, without useless and degrading suffering. Everyone has the right to a dignified death.

Certainly, the end of human life is not easy in any of the countless possible situations that can arise from it. But, at least it seems imposing the continuity of a survival laden with indignity and without the least psychophysical integrity at the expense of embracing the decision-making autonomy of the patient who wishes to have an early death, translates the disrespect to a series of rights that they are inherent to it, and, on the other hand, it does not hurt, as said, the right to live, but it denotes the option to experience the last act of life, which is death, autonomously. That is what Philippe Ariès asserts in his work "Man before death" when he explains that "Death must only become the discreet, but worthy, exit from a serene living, from a solicitous society that it does not crush or disturb the idea of a

biological passage, without meaning, without effort or suffering and, finally, without anguish." (ARIÈS, 2014, p. 827).

It is true that to deal with the dilemma of death is to meet one of the most difficult "parts" of human existence, and that is said for those in which death theoretically approaches (terminally ill) and for those who need to be together with them. On the subject, moreover, explains Pessini (2009) that human life, from beginning to end, is coated with a series of events and a series of feelings, and give goodbye to someone who is about to die is not easy.

Logically, that pain must be experienced, however, not even the suffering of peers can justify someone's obligation to endure an unworthy end of life and/or unwanted treatment. Still less, desires arising from therapeutic obstinacy, or, why not, impositions from the State, so that survival is maintained.

It is clear that at no time is the obligation of the medical professional to contradict their convictions to put into practice the desire of others, as that is not allowed either by the legal order or by the ethical precepts that guide the profession, or by the professional class norms. Even if the hypothesis was (or is) legal, the doctor is under no obligation to violate their conscience. But, in the multiplicity of ideals that exist, many professionals agree with the absolute primacy of the patient's autonomy in the cases of terminal and suffering stages, and the tendency is increasing by respecting the ethical principle of autonomy, which despite paternalistic optics remain in the class. So, as already occurs in other cases, and even in the case of early death in other countries, if the attending physician refuses to comply with the patient's wishes, there must be the right to resort to a second professional, to do so without the injury to its ethical, moral, and even personal precepts.

Fortunately, health relations are currently migrating from a paternalistic ethic towards the affirmation of decision-making autonomy as a power of self-determination over one's own body concerning issues related to life and

health. So much so that autonomy, as explained earlier, was elevated to the category of basic principle concerning biomedical ethics and, in truth, follows the path of the patient empowerment over their life and health.

Besides, what is sought as the ultimate goal is the protection of decision-making autonomy, privacy to decide on intimate matters, and the moment of death certainly fits into this concept, so that what should be prioritized, under this meander, is their dignification, through the greatest possible respect for the patient's self-determination, effecting their death according to their values. If the patient's will, an expression of their decision-making autonomy, is the anticipation of this very delicate moment, to shorten their suffering, it must be respected (although it should never be imposed). And, how that respect can be offered to the decision-making autonomy of the patient who prefers to anticipate death rather than live it through suffering that seems unsustainable, and contrary to their values, is the legalization of the conducts through which one can reach it, imposing the necessary limits to the effectiveness. The path to doing so will certainly be winding since the subject is delicate and remarkably controversial, but it is essential and urgent to reflect on it.

Ariès (2014, p. 795) asserts on the subject:

The doctor, who for a long time was, with the priest, the witness, and the announcer of death, only now knows it in the hospital. The practice of non-hospital medicine no longer gives the experience of death. Since then, the best-informed doctor will, as is believed, better prepare their patients and will be less tempted to take refuge in silence.

The essential issue is the dignity of death. This dignity requires, in the first place, that death is recognized not only as a real state but as an essential event, which is not allowed to be canceled.

One of the conditions of this recognition is that the dying person is informed of one state.  $[\dots]$ 

Are we, therefore, on the eve of a new and profound change in the face of death? Was the rule of silence beginning to become obsolete?

Thus, even those who are against the anticipation of death embodied in euthanasia or assisted suicide, agree with the need to preserve the

psychophysical integrity and, therefore, the bodily integrity of the terminal patient, to the extent that it is accepted, by the absolute majority of people, the treatment is only palliative, at the end of life, in which case the option for orthothanasia can be denoted.

Bodily self-determination, just as it is for euthanasia and assisted suicide, concerning the possibility of basing the possible realization of a "right to abortion", is nothing peaceful. Quite the contrary, it reveals the always striking clash between those who defend women and their right to their bodies when it comes to interrupting an unwanted pregnancy and those who reject such an ideal, based, above all, on the "right to life" of the fetus.

Indeed, the defenders of a possible right to life of a fetus put themselves in a very clear and incisive way in the sense that there is no possibility of embracing the woman's right to bodily self-determination to perform an abortion, for this right, in theory, collide with a fundamental right (life), owned by someone else (the fetus), and that, therefore, should not be accepted so that the latter would prevail.

However, the equally clear and plausible ideal of those, or, for the most part, of those who defend the right of bodily self-determination, even for the purpose of abortion, based on the conviction that there is a right to their own body, and based on the idea that such a right gives them subsidies to do so.

On the subject, Garcia (2010) reiterates the importance of considering the autonomy of women as well as of all individuals. Still, the importance of perceiving women as human beings invested with qualities and defects, and holders of rights, forgetting the sometimes sexist ideal that women should live in a colorful and perfumed world, oblivious to the most controversial events.

It becomes necessary, therefore, to investigate the issue of abortion in a broader context, which incorporates, in addition to the biological aspect, the physical, moral, and emotional aspects, and in this regard, it is considered what was demonstrated in Freitas (2010). Certainly, all matters that, in addition to the legal nature, are issues of social order, need to be considered, taking into account all the variables of such large concerns, and it is precisely there that, as a consequence, it comes into guides the right to bodily self-determination.

Furthermore, on abortion, points out Cohen (2012, p. 196):

This is not so because the woman is identical to her uterus or because she has it, or because she is or possesses her fetus, but because the experience of pregnancy constitutes a fundamental change in her personification, in the physical, emotional, and symbolic levels and, therefore, in their identity and feeling of individuality.

Thus, pregnancy is an extremely peculiar experience and, why not say, difficult for all (or almost all) women. The body changes, and, mainly, the shift in the psychological identity is very significant, and this in the case of women who desired that pregnancy and who used their body self-determination to plan, or, at least, accept that pregnancy.

This change in identity, if unwanted, is, for those who defend the right to have an abortion, an event that leads to the damage of the women's fundamental rights. It is at this moment that the defense for the woman's right of body self-determination surfaces, so they, as an autonomous person who is supported by their right to their own body, decide whether or not they want to carry out the (unwanted) pregnancy.

Thus, it is noted that all the issues that permeate situations emanating from decision-making autonomy and the consequent right to body self-determination are not at all easy to be debated, nor is it easy to defend any of the points of view related to them. However, it is essential to promote discussion about such matters so that, one day, they may be seen without preconception covers or shields, seeking only the protection of the human being, of the person, in their dignity.

#### **5 CONCLUSION**

As a rule, the human being seeks autonomy. Thus, try to be and, in fact, be able to be autonomous to control the outcome of their life. Therefore, the decision-making autonomy explained in the course of the article as emanating from a right to privacy, needs to be respected, within the parameters of legal science, primarily because it is essential in decisions located in the privacy zone of individuals and which, assuredly, generate controversies, due to the complexity of the subjects. It was found that talking about autonomy is not an easy task, and the term is not a single concept. It is noted, despite this, the unmatched importance that autonomy has (and the consequent right to exercise it), in a concrete way in people's lives, in the absolute case that the topic of discussion is merely theoretical.

Therefore, from all of the above, some considerations can be made: First, the need to think about the right to privacy in terms of the national legal system, and from there, obviously, to think of decision-making autonomy as a subsidy so that the individual can make their choices in a field of their decidability.

In this sense, it is thought that the right to one's own body must be truly recognized, not because it means that people can or should do with their bodies what they want, without any limit, as if it were a mere commodity, but because the person's body is, after all, the person, and in that way, that person's feeling of control over the body is fundamental.

Therefore, it is reflected that the decision-making autonomy, previously described, gives the individual powers to exercise their body self-determination, insofar as it provides the necessary means for them to take possession of their body and make decisions with personal and private motivation. For those reasons, it is believed that decision-making autonomy does subsidize the existence of what is called, then, bodily self-determination.

The right to one's own body, already mentioned, needs to be taken into account within this parameter because it can be said that it is garrisoned by the protective power offered to the personality rights.

Furthermore, it is considered essential to foster the debate on the themes that emanate from the analysis of decision-making autonomy and the consequent right to bodily self-determination, such as those described in the text (mainly dignified death and abortion), in addition to many others that can be cited, as is the case of the option for medical treatments (or not).

Even if you disagree with the ideal of decision-making autonomy concerning those matters, it is only through their study that certain myths and barriers, rooted in common understanding, will be surpassed. In fact, with the analysis of the emblematic studies presented, one can perceive the dimension of the problem displayed, which asks for a solution that meets the defense of personal dignity, clearly emerging the notion of effectiveness and materiality that the study proposes.

Finally, it can be considered that the importance of decision privacy is undeniable, supporting and empowering the person so they can make their choices based on their way of life and performance, and which safeguards them in their identity and consequently in personal dignity. Based on this assumption, it is believed that it is necessary to rethink some imposed paradigms so that the most profound possible protection of human beings can be achieved, as a person and subject of rights.

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# DECISION-MAKING AUTONOMY IN THE DEFENSE FOR THE RIGHT TO DIE WITH DIGNITY

#### **ABSTRACT**

This article aims to investigate the possibility that the terminal patient, with decision-making autonomy, can claim the right to die in a dignified manner. To achieve the purpose, a qualitative exploratory-explanatory bibliographic research was carried out using the deductive method. It is concluded that, although the issue is controversial, the decision-making autonomy deserves to be taken into account, including in the realization of the right to die with dignity, since it seeks to protect the human being in the most intimate aspects of their life and, even because, choosing for dignified death does not mean giving up the right to life.

Keywords: Decision-making autonomy; privacy; personal dignity; dignified death; dignified life.

#### 1 INTRODUCTION

The study in question has as its central theme the analysis of the decision-making autonomy of the terminal patient as a guide for the defense of their right to die in a dignified manner. The before-mentioned autonomy, as will be seen in the course of the essay, arises from a new analysis made from the right to personal privacy and gives human beings ammunition in defense of their identity, and consequently, of their dignity. It has distinctive relevance in decisions of an intimate and private nature, and, for this reason, we will seek here to reflect it to the right to die with dignity since there is no doubt that death is one of the more intimate and delicate moments in the dislocation of human life.

It is made clear, in advance, that the dignity to which we intend to speak is that built from decision-making autonomy, that is, we seek to understand dignified death through the dignity criterion earned by each person, arriving, then, to the concept of personal dignity. Therefore, it is not intended to present dignified death as a concept created from the perspectives already established for the "dignity of the human person". Likewise, it is not proposed to enter specifically into the discussion concerning the ill who cannot express their autonomy, for any reason, since the heart of the study raised here refers precisely to the expression of such a right.

The justification of the agenda focuses on the topicality of the theme and the innovative perspective related to the decision-making autonomy to be explained. Still, the importance of the research lies in the always controversial issue concerning the possibility of choosing the best time and the best way to die, which has been causing controversy for a long time, in the most diverse areas of knowledge, including legal science and, at least to what it seems, will still cause, given the seriousness of the matter.

The study's problem is, therefore, in the following question: can the terminal patient's decision-making autonomy underpin the realization of a possible right to dignified death (with personal dignity)?

The objective is, in general, to analyze the possibility that the decision-making autonomy of the terminal patient can support their right to die in a dignified manner. Specifically, bring necessary clarifications about the innovative concept called decision-making autonomy, elucidate the concept of dignified death, and consider the possibility that the terminal patient can choose the best way and the best time to die, worthily, according to their values, basing themselves, and equipping themselves, for that, in their decision-making autonomy.

For this to be possible, the study will be organized in a way that, at first, the assessment of decision-making autonomy will be made; in a second step,

what will be considered is the definition of dignified death (with personal dignity); and, in a third moment, the hypothesis that the decision-making autonomy of the terminal patient can base their right to death with personal dignity will be investigated.

Regarding the methodological aspect, the research is based on technical, rational, and systematic procedures, with the intention of a scientific basis, allowing to reach logical foundations related to the investigation. Finally, we take care of exploratory-explanatory, qualitative bibliographic collection research, in which the deductive method is employed and in which the intention is to explore and describe the subject in question, revealing the possible solutions to the presented dispute, without, however, having the purpose of exhausting the theme.

# 2 DECISION-MAKING AUTONOMY: REDISCRIPTION OF THE RIGHT TO PERSONAL PRIVACY

From the foreground, it is emphasized that autonomy (and the right to autonomy) is a mark of struggles and historical achievement and can be seen more clearly since its visualization as freedom in ideals arising from liberalism, emanating mainly in (and since) the 18th century.

Nevertheless, it is essential to emphasize that the decision-making autonomy to which it is intended is not part of an ideal that is too individualistic, in the liberal molds, of a displaced individual, uprooted from the social whole. It transcends the concept of the struggle for the non-interference of others, or the State, in the plan of choice of each human being, and seeks to contemplate the autonomy that allows the construction of the human being's own identity in the search for personal dignity, as already emphasized by Freitas and Zilio (2016a).

Thus, the analysis that will be carried out in the study takes into account the existence of autonomy that is not based on already famous ideological conceptions but brings a new means of ideological and theoretical approach concerning the theme, following what was explained in Freitas and Zilio (2016a).

The autonomy to be sought is, then, the one that gives weapons to the construction of the personal identity of each individual, which enables the externalization of personal desires in the making of important decisions of an eminently personal nature (hence the reason why it is also known for decision privacy), and contributes to the empowerment of the person about themself, about their body, and their decisions. Cohen (2012) conceives that such autonomy involves what she calls an "intimacy zone". For her, this is an area of real conflicts and in which the very principle of an individual right to privacy is contested.

It should be noted that the zone of intimacy highlighted by the author brings to light the idea of peculiar issues of the individual's most particular field and, consequently, the respective decisions.

To understand the decision-making autonomy, as outlined by Freitas and Zilio (2016a), it is necessary to understand the right that serves as a foundation, namely, the "right to personal privacy".

In the right to personal privacy, one can denote the existence of two important dimensions, each with its peculiarities. Cohen (2012) makes each one explicit and, according to the author, the first consists on the right to be left in peace, and the second, on the decision-making autonomy, which the study is based.

Thus, the first of the dimensions explained does not raise any significant challenges according to what was examined in Freitas and Zilio (2016a). As mentioned, it concerns the right to be "left in peace", which is the

right not to suffer intrusion or surveillance without there being, at least, a just reason. About this dimension, Freitas and Pezzella (2013) mention that it is not a matter of recognizing yet another individual right, in liberal terms, but of protecting personal privacy, which precisely makes it unique and identifies it among all the others.

Also, the second dimension carries within more controversies, through what is reached in Freitas and Zilio (2016a). It is, therefore, the "decision privacy", or, also called, "decision autonomy", which is the right not to be subjected to improper control, including concerning possible regulations by other individuals, such as the one considered in Cohen (2012).

Therefore, the first dimension is referred primarily to the possession and dissemination of information, and the second, to the decision-making autonomy related to the intimate aspects of each individual, which brings together, even, the intimate availability, according to Cohen (2012) and Freitas and Zilio (2016a), and makes it more criticized.

As stated by Freitas and Pezzella (2013), bearing in mind the second dimension presented, the main criticisms regarding individual rights in general, and specifically regarding privacy rights, refer to the liberal society/ state model, which, supposedly, would gain strength by protecting privacy, in its dimension of decision-making autonomy.

However, Freitas and Zilio (2016a) argue that this is not the issue. Cohen (2012) opposes the opinions that emphasize that deliberations based on decision autonomy are deliberations that take into account a collection of separate or isolated individuals.

According to Freitas and Pezzella (2013), the right to privacy designates the individual as the center of their decision-making process and does not, therefore, determine an ethical or ideological choice to be followed, but a sphere of self-determination in that each one can and must carry out

their concrete identity. That has already been reported by Freitas and Zilio (2016a). Furthermore, individual options can be made for their reasons, as seen in Cohen (2012) and Freitas and Zilio (2016a), and even there is no pressing need for them to be justified.

It is evident that the criticisms have plausible content, but what we want to make explicit is that it is not up to the definition of decision-making autonomy to conceive of isolation, but, truly, the individual's look at oneself making decisions that meet the needs of their values, which does not make it dissociate from the commitment to the whole at all.

In reality, as explained by Freitas and Pezzella (2013), the collectivity idealized as a mere sum of people in which each one defends nothing more than their interests is reflected as a denial of the possibility of the existence of a social whole, and if it were that way, the only possible identity among the members of that whole would be the vocation to possess, which is intended to be inherent, according to what they point out, to "human nature".

Cohen (2012) and Freitas and Pezzella (2013) clarify, which is not what happens with decision-making autonomy. Thus, they denote that it is not correct to subordinate the right to privacy, especially in the dimension of decision-making autonomy, to the connotation of an uprooted individual, because as it is gathered in Freitas and Zilio (2016a) that, what is sought is the safeguarding of the personal autonomy's core, to the detriment of what can be called "community norms" which, in certain situations, can be abusive in what is pertinent to that dimension, and, also, given the majority's own will, which is often disrespectful in terms of diversity.

In this regard, Cohen (2012) brings to light the idea that the privacy rights, protectors of decision-making autonomy, in addition to allowing the individual's identity to be safeguarded, also allow protection in the search for what they believe to be their conception of the good, as well as protecting what she, the author, calls the principle of authenticity. Thus, even though

personal needs conflict with the majority's interpretation, personal privacy rights protect them (except in specific cases in which universal moral principles are violated). So, the right to be different is protected.

It should be noted that the heart of the matter lies precisely on preserving the intimate core of being, which does not prevent it from exercising collective values, but it does protect its values to the detriment of eventual abuse.

Thus, privacy rights guarantee, as announced by Cohen (2012), to all preconditions to build integral identities that they can evaluate as to their own. From the other perspective, as they equally guarantee legal personality and decision-making autonomy to all, those rights protect the demand of each individual, although they are "different" from the others. Likewise, through what is gained in Freitas and Zilio (2016a), they safeguard the personal dimensions of each person's life, protecting them from undue interference, and thus ensure the processes of self-development and self-realization involved in the question of the formation of personal identity.

Especially because, in reality, the individual's identity is not formed only by group values. For Cohen (2012), in different societies, privacy rights play important roles in protecting individuals' capacities for the formation, maintenance, and presentation to others of a truly coherent, authentic, and distinct self-concept.

However, the exercise of explicit decision-making autonomy presupposes the right to information, according to Freitas and Zilio (2016a), that is, so that the subject can make choices based on their decision-making autonomy, one needs to be very well informed about the paths to be taken, as well as on the consequences of making each decision. That requires, as already considered by the authors, to empower people to act autonomously, informing them, therefore.

Still, Beauchamp and Childress (2013) clarify the need for information for the development of autonomy in a specific way concerning biomedical ethics, and it is worth bringing their considerations here, as they enrich, and a lot, the discussion. For them, autonomy establishes a right of authority to control their destiny. The authors, in a positive perspective of understanding, consider the principle of respect for autonomy that there is an obligation, also positive, of respectful treatment in the disclosure of information and the consequent encouragement of the autonomous decision. Thus, many self-sufficient actions require the assistance of others to make the options accessible. Especially in biomedical ethics, respect for autonomy requires professionals to clarify information, as well as to verify and ensure clarification and voluntariness, and to encourage appropriate decision-making according to the ideals and beliefs of each person.

In the same way, because it is relevant in matters of a uniquely and truly personal nature, asserted decision-making autonomy presupposes the control of each person over their own body to protect their dignity, according to Freitas and Zilio (2016a). Thus, as the authors refer, in the exercise of decision-making autonomy, each one has the right to take possession of their own body to the detriment of the opinions of society, the community in which they live, and even the State, as it is not up to them to intervene in an invasive manner in the intimacy of people, but it is the State responsibility, to guarantee conditions for the regulated exercise of autonomy, acting, in this aspect, in a positive way.

Freitas and Pezzela (2013) demonstrate the issue of reflecting on decision-making autonomy about the right to one's own body in the sense of its reintroduction in the theme of privacy. Not, obviously, in its "individualistic - possessive" dimension, as if personal attributes, including the body itself, were individual properties, or commodities to be traded, as described by Macpherson (1979), but as exemplified by Freitas and Pezzella (2013), from

the concrete analysis of the body as what can be obtained in Goffman (1971): a territory of itself.

In this perspective, it is also necessary to reiterate Goffman's (1971) always fit thought, in the sense that the feeling of control over one's own body is fundamental for an integral perception of oneself, as well as for one's self-confidence. Assuredly, to perceive globally as an individual, you need to take into account the exercise of empowerment over one's own body so that, consequently, control over the body becomes essential to the configuration of the own identity, just as it is for the preservation of personal dignity.

Finally, but with absolutely less importance, it is worth emphasizing that the moment of death fits perfectly in the description of intimacy exposed before, in which the protection of decision-making autonomy is so relevant. It is even worth mentioning that this moment is, perhaps, the most intimate and deserving of respect for the moments experienced by the human being, and, precisely for this reason, whenever possible (and one should try to be possible), it needs to be faced through personal dignity preservation of the individual in question. The criterion of death with personal dignity is, moreover, what the study intends to examine and explain subsequently.

### 3 DEATH WITH PERSONAL DIGNITY: NECESSARY NOTES

It is not uncommon for discussions about "dying with dignity" or "dignified death" to emerge, and such controversies arise both in the bioethical, legal, philosophical, and even political spheres. Nevertheless, the criterion of death with dignity is still sometimes obscure and, because of that, we are trying here to at least contribute to its elucidation, using as a parameter what we prefer to call personal dignity.

A dignified death is the one faced according to the personal dignity of each being, under the provisions of Freitas and Zilio (2016b). Thus, according to the authors, personal dignity is the condition taken into account by each being to live with dignity, and that, independently of the generic concepts about what would be the "dignity of the human person".

Indeed, it is known that death is an event inherent in the vital process itself and a moment that, inevitably, will need to be experienced. In turn, death with personal dignity is what happens at the moment chosen by the holder of life itself, to safeguard their dignity, through what has already been reiterated by Freitas and Zilio (2016b).

Regarding the patient who is already in a terminal stage of life, Kübler-Ross (2008) explains that, unfortunately most of the time, they are treated as someone mysteriously without the right to express an opinion, in a way that often, it is another person who decides on if, when, and where the patient should be hospitalized. In an extremely proper way, the author mentions that it would cost so little to remember that the ill person also has feelings, opinions, desires, and, consequently and obviously, the right to be heard. That is precisely where the criterion of personal dignity comes in, while that seeks to respect what the person understands to be good for them, even at the crucial moment when death is approaching completion.

Death with dignity is a pleaded right and has an extremely plausible content. According to Borges (2001), the right to die in a dignified manner should not be confused with the right to die, quite simply. Thus, the right to die with dignity brings together the struggle for several rights, such as dignity, freedom, autonomy, conscience, and refers to the desire to have a human death without the anguish and agony of prolonging useless treatment. In the author's view, defending the right to die with dignity does not mean supporting any procedure that anticipates or causes the patient's

death but taking into account the recognition of their freedom and selfdetermination.

Thus, the preservation of life only taking into account the biological criterion, neglecting the quality to be provided to the individual, according to Sá (2001), can no longer be considered nowadays, which has also been considered by Freitas and Zilio (2016b). Thus, prolonged life would be justified, for Sá (2001), if it brought some improvement and provided it did not hurt the dignity of living and dying. If this is not the case, dignified death must be accepted since it safeguards all the other constitutive dimensions of an individual and not only the biological question.

As Ribeiro (2006) reiterates, and according to Freitas and Zilio (2016b), dignified death can even be considered a human right, which is understood as death without pain or anguish, by the will of the holder of the right to live and die.

Consequently, it is believed that the concept of dignified death - or, as we prefer to name it, death with personal dignity - is linked to the conduct of facing the death process in an altruistic way and concerns to the act of preserving the terminal ill patient granting them a more peaceful and preserved death, when there is no possibility of conserving their life, with dignity, according to Freitas and Zilio (2016b).

Thus, the aim here is to explain what "dying with dignity" would be, according to the conception of each terminal patient, by their values, among which, the autonomy to discern about death, when in any case it is imminent, as can be noted, also, in Freitas and Zilio (2016b).

Therefore, the objective of the study is, from now on, to analyze the decision-making autonomy as a possible basis for the configuration of dignified death (with personal dignity).

#### 4 THE TERMINAL PATIENT'S DECISION-MAKING AUTONOMY AS A FOUNDATION FOR EFFECTIVENESS OF THE RIGHT TO DEATH WITH PERSONAL DIGNITY

Once the issue concerning decision-making autonomy has been addressed, and the concept of death with personal dignity has been explained, from the lines that follow, we seek to ponder the issues in a joint and weighted manner, to clarify, even in an embryonic way, if the explicit decision-making autonomy of the terminal patient can underpin the realization of a possible right to dignified death (with personal dignity).

As seen, decision-making autonomy has special relevance concerning intimate aspects of the life of each human being, so much so that Jean L. Cohen has already mentioned that this autonomy hovers in what the author calls "zone of intimacy". Well, the right to have one of the most important "assets" to any individual: the body itself, opting for the time to die, fits perfectly in this concept of "intimacy zone" brought up by the author. Death is, therefore, an extremely intimate event in the life of the individual and must be experienced with the highest possible respect.

Notwithstanding, currently, as listed in Freitas and Zilio (2016b), the technologies employed in the medical treatment of terminally ill patients can cause vaster pain and suffering than the very illness that afflicts them, prolonging the process of death, to the detriment, sometimes, of the sick person's own will. According to the authors, it is at that time that the questioning about the possibility of the existence of the right to die in a dignified manner arises with greater fervency, death occurring by respecting the autonomous decision of the one who is the holder of the life.

Regarding this issue, Diniz (2007) considers that, even though health professionals are the ones who most intensely deal with death, on the other

hand, they resist recognizing it as an inexorable fact of their existence, so that they are often socialized in an *ethos* that mistakenly associates death with a real failure.

What is brought up, according to Freitas and Zilio (2016b), is the possibility to dignify the moment of death, by the will of the terminal patient, so that it (death) occurs respecting their values and according to the conception of death with dignity defended by the patient, despite the opinion or objection of other people, the community, society, or the State, since the individual in question, and only them, can determine what is worthy for them and what respects their beliefs.

Although the study does not have the scope to specifically defend euthanasia or any of the behaviors of related nomenclature, the death that occurred according to personal dignity is worth mentioning what, with mastery, explains Martínez (2008, our translation). For the author, the subject considered here is fundamental: knowing how to place personal autonomy concerning one of the essential issues of life, which is the decision about when and how to cease to exist, in the search for a smooth separation from life (the author refers to the nomenclature used by Francis Bacon in this last statement).

In fact, as Freitas and Zilio (2016b) have already pondered, often the question that the right to life cannot be seen as a duty, an obligation to live, but a right to be exercised in harmony with other values, such as dignity and autonomy, appears in legal and bioethical discussions.

Ribeiro (2006) states that the right to live, for it is a potestative right, can only be renounced by its owner. If it were not renounceable, it would not be a right but a "duty" to live. And as a "duty" to live, it would bring legal consequences different from those known today, starting with the punishment of attempted suicide, the prohibition of extreme sports or risky

activities, and would trigger the mechanization of life beyond life, generating inhumane treatments and degrading to the ill.

As already stated by Dworkin (2003), it is necessary to attribute the real importance to how death occurs, hence why the right of people to end their lives is sought according to the parameters that have always guided them, as stated by Freitas and Zilio (2016b).

Note the relevance of reflecting on the theme through decision-making autonomy so that decisions are made freely (and consciously) and with due respect from all.

Thus, tolerance is needed about the different ways of life, a tolerance to be put into practice inclusively by the medical professionals themselves, by family members, by the State, and by individuals in general, especially in coping with dignified death - with personal dignity, according to the very conception of the terminal ill patient, and that is what Freitas and Zilio (2016b) acquiesce. It is necessary to keep in mind that, while for many people it is worth what can be called "fighting to the end", for others, having dignified and autonomous death is the priority means of guaranteeing the dignity of life as a whole.

Indeed, Martínez (2008, our translation) expresses that a person's interest in following their convictions at the end of one's life is a manifestation of the rights to privacy and freedom. According to him, death is for each one of the most significant events in life itself, and many of those individuals want this last moment to reflect their convictions, and not the convictions of other people, imposed precisely in a moment of extreme vulnerability as is the moment of the end of life. However, people face death in different ways. Yet, according to the author's understanding, none of those ways can be considered irrational any more than any way of facing death can be imposed on anyone, neither by doctors nor by the government.

Thus, it is necessary to preserve respect for the will of the sick, now terminal, as Freitas and Zilio (2016b), even more in pluralist societies, in which there is certainly a great diversity of cultural and philosophical conceptions that, assuredly, generate different notions about death and its intricacies.

It can be said, as Freitas and Zilio (2016b) have already reiterated, that the right to life is a right of indisputable importance. It happens that, in extreme situations that characterize the terminality of life, the right to die with dignity (expressed here as personal dignity) preserves several rights of the individual who pleads for it, and it is shown to be inherent in the right to live, with dignity.

Reflect May and May (2014), that constitutionally protected life is about dignified life. For the authors, starting from the premise that life cannot be considered as an unavailable good, it can be understood that it is subject to constitutional protection as long as it is dignity.

Undoubtedly, it is important to note that, according to what has already been defended by Freitas and Zilio (2016b), dignified death, carried out through the autonomy of the holder of life, has its space when death is imminent, and the suffering of prolongation of the death process proves to be unsustainable, from the point of view of the patient.

As Freitas and Baez (2014) well ponder, it is necessary to emphasize the patient's decision-making autonomy as the only means for the realization of a dignified death. Otherwise, what would happen would be a stolen death which under no circumstances is justified, according to the understanding expressed by the authors and according to what can also be obtained in Freitas and Zilio (2016b).

Likewise, the decisions to be made in cases such as those under comment need to be made without any external pressure, leaving the patient to discern on their body and life. Resuming the argument, it is clear that, according to Freitas and Zilio (2016c), it is necessary to abandon old dogmas, facing the right to live through a humanized perspective, prioritizing life's dignity, because, according to the authors, die in a dignified way, or die with personal dignity, is not conduct opposed to the protection of life, being, therefore, the right to die with personal dignity, in face of the right to live with the same dignity.

Still, according to what Freitas and Zilio (2016c) defend, dignified life can and should be pursued. It happens that death is, moreover, the last act of life, so death with personal dignity needs to be seen as an inherent act in the very process of living, with dignity (see that dignified death is part of a dignified life and therefore, it must be sought and respected).

Therefore, based on all of the above, it is necessary to consider: why not preserve the human being as a being with decision-making capacity, as an individual endowed with decision-making power over peculiar moments such as the moment of death; as an individual who sees their life and their body not as their properties, as a commodity, but an individual who knows the purposes that guided their life, who knows their limits, and who deserves to determine themself on occasions when them, and only them, can do it with total respect for themself? That is the doubt that is present, and that needs to be discussed.

#### **5 CONCLUSION**

As a central target, the present essay sought to reflect decision-making autonomy and the possibility that it can serve as an element of defense and a foundation for the consolidation of the right to die with dignity. Part of the analysis of what dignified death is and the understanding of decision-making autonomy to conclude that, in the case of personal and private decisions, the specified autonomy deserves to be highlighted.

Themes that permeate discussions about autonomy and the possibility of choosing in the light of certain situations always generate controversies. Thus, the possible right to death with personal dignity, discussed here, awakens conflicting understandings and, despite being debated for a long time, remains current and very important. It was also attempted here to bring a new way of analyzing the theme embodied in decision-making autonomy as a dimension emanating from the right to privacy.

Thus, it can be said that decision-making autonomy, or decision-making privacy, is what protects human beings in their most intimate field, giving them the necessary empowerment to make decisions that meet their will ultimately and pure.

From then on, death is related to personal dignity. Death with personal dignity is related to death that occurs according to the values raised by the terminal ill patient according to their personal beliefs and experiences, detached from the conception of what the majority considers "fair", since it is conceived that death is an extremely private and intimate moment and everyone has the right to know what is worthy for themselves and what must be done (or not done) for that dignity to be preserved.

Because of that, we worked specifically with the concept of dignity constructed through decision-making autonomy. As a consequence, dignified death, when made explicit, corresponds to death with personal dignity, and the analysis of the theoretical explanatory perspectives of the term "dignity of the human person" does not fit.

Therefore, it is important to say that the decision to die with personal dignity does not counterpoint the right to life or announces a renunciation of the right to live since it is conceived that the right to live with dignity and the right to die with dignity are, therefore, faces of the same right. Thus, the patient, when choosing to die with personal dignity, chooses to live their last

act of life, which is precisely death, in the way they believe to be the best, using their right of privacy in their decision-making autonomy dimension.

Therefore, according to the understanding stated, it can be manifested that the terminal patient, armed with external decision-making autonomy as one of the pillars of their right to privacy, has the prerogative to choose to live the moment of their death as they consider to be dignified. It is believed that this decision does not confront their right to live in such a way that the autonomy expressed, so necessary in private subjects, under this bias, can support the right to a dignified, peaceful, and humanized death. It should be noted that the heart of the matter lies in the importance of autonomy and the defense of the protection of the autonomy of each human being and all human beings. We do not speak in defense of death, but in defense of human beings, in defense of their right to discern, to decide, to empower themselves, and to make the decision that is best for them, according to what they consider to be worthy for its existence, therefore, for the truth, death is a solitary event and must, then, occur according to the desire of the individual who is experiencing that situation.

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# THE AUTONOMY OF THE WILL AND THE RIGHT TO DEATH WITH DIGNITY

#### **ABSTRACT**

This article aims to question whether the autonomy of the will can support the right to a dignified death. The objective, then, is in line with the investigation of the (non) possibility that the autonomy of the will, to the detriment of the right to life, as a fundamental human right, can serve as a scope for the practice of euthanasia. For that, a qualitative exploratory-explanatory bibliographic research was carried out, using the hypothetical-deductive method. The results achieved with the research are related to the exploration of the theme under analysis from a new perspective, namely, human dignity in its double dimension. The conclusion obtained is that there are very wellfounded theoretical foundations for those who believe that the right to life should prevail, not least because such a right is part of the basic dimension of human dignity, being, therefore, a fundamental human right, as for those who defend that dignified death should prevail, based on the right of selfdetermination of each individual inherent to their autonomy of the will. The contribution achieved refers precisely to the study carried out on topics as important as the autonomy of the will, the right to life, and human dignity, which, in one way or another, are always enlightening within the legal field. Keywords: autonomy of the will; human dignity; life; death with dignity; euthanasia.

#### 1 INTRODUCTION

The current study has as its central theme the dignified death and the controversy arising from the struggle between the autonomy of the will and

the possibility of choosing a dignified and humanized death, instead of the protection of the right to life, as part of the basic dimension of human dignity.

This subject has an interdisciplinary impact, and in legal science, it has an even more controversial connotation, precisely because of the clash between such elementary rights, hence the justification of the need to always be brought to the agenda.

So, it is intended to argue what should prevail in a situation of pressing death, dignified death based on the autonomy of the will, or prolonged life, even if it is full of pain and suffering, based on the fundamental human right to life?

The issue we seek to investigate, therefore, is based on the verification of the possibility of choosing death with dignity, based on the autonomy of the will, to the detriment of the protection of the right to life. The counterpoint focuses precisely on the possibility that there is the right to the option for humanized death, free from pain and suffering.

Therefore, the objective is to analyze the autonomy of the will as an assumption of the dignity itself, of human dignity in its dimensions and the right to life as a fundamental human right, and dignified death, in order, finally, to arrive at the clash object of the study, centered on the possibility of choosing to die with dignity. Thus, the aim is to contribute to the clarification of the theme, which is by nature contested.

To do so, a study will first be made about the autonomy of the will, which, theoretically, would be the scope for the configuration of dignified death as well as the right to one's own body as part of the rights of the human personality. In a second step, it will be instigated about fundamental human rights, as part of the basic dimension of human dignity, based on the theory of the double dimension of dignity, in the light of the understanding of Narciso Leandro Xavier Baez, and, just ahead, about the fundamental human right to life. Then, the study is guided by the conceptualization and specific

explanation of dignified death, euthanasia, and related concepts. Finally, the article focuses on the specific issue of the conflict between the fundamental human right to life, and the autonomy of the will, when the possibility of carrying out the so-called dignified death is possible.

As for the methodological aspect, the research is based on technical, rational, and systematic procedures, with the intention of a scientific basis, providing logical foundations for the investigation. Finally, we take on an exploratory-explanatory, qualitative bibliographic collection research, in which the hypothetical-deductive method is used, and in which the scope is, based on hypotheses, to explore and describe the subject under discussion, expressing possible solutions for the confrontation presented, without, however, exhausting the theme.

# 2 AUTONOMY OF THE WILL: INTRODUCTORY ASPECTS

From the foreground, it is brought to light that the principle of the autonomy of the will comes from the ability of each human being to rationally discern what would be good or bad for them, and can therefore lead their life according to their choices, when those, logically, do not enter into the sphere of the rights of others.

Along this narrow path, it would not be up to the State, the collectivity, or any entity to establish the pathway that each person should follow, the values that he/she should believe, or the attitudes that he/she should have, and it is up to each human being to discern the directions of their lives they must take, according to their subjective options (PIRES; DOS REIS, 2010).

In the same vein, the right that each person has to determine themself in certain situations is part of their right to privacy, in the sense that there are spheres of protection of their personality that concern only the person involved (COHEN, 2012).

The idea of autonomy is linked to the protection of dignity since to deny a human being the ability to decide the way they prefer to live, the projects they aim to accomplish, and the way to conduct their life would be to frustrate the possibility of the existential realization of each being (SARMENTO, 2010).

Thus, according to the Kantian understanding, freedom, or more deeply, autonomy, and human dignity itself, have always been close figures, being that the foundation of this and all rational nature (KANT, 2003).

So much so, that the author explained that morality exists in the relationship of actions with the autonomy of the will, with the ability of the rational being to legislate and to submit to the legislated law, being treated as an end, and never simply as the means (KANT, 2003).

Autonomy expresses dignity and stems from people's freedom and equality. Thus, individual self-determination and the right to respect and consideration are part of the content of dignity. Everyone can choose their existential projects and should not, therefore, suffer discrimination, nor due to their identity and choices (BARROSO; MARTEL, 2010).

In this way, dignity as autonomy includes the power of self-determination and the right to discern the direction of one's own life and to freely develop one's personality. In addition to the idea of autonomy, there is someone moral, capable of self-determination, making plans, and putting them into practice (BARROSO; MARTEL, 2010).

There are decisions that the State can legitimately take, in the name of different interests and rights, but deliberations about a person's life, existential choices, and very personal options, as long as they do not violate the rights of third parties, cannot be suppressed from the individual, under penalty of violating their dignity (BARROSO; MARTEL, 2010).

Although it is not the focus of this study, it must be said that for some authors, private autonomy and the autonomy of will can be treated as synonyms.

Thus, private autonomy would have two dimensions: the first related to existential freedoms, and the second related to contractual freedom and legal business (STEINMETZ, 2004).

For other authors, the autonomy of the will, despite having similarities, is not to be confused with private autonomy, since there is a significant difference between them, highlighted by the focus of the phenomena in the perspective of legal nomogenesis. Thus, the autonomy of the will would have a more subjective, psychological connotation, whereas private autonomy would mark the power of the will in an objective way, more, so to speak, concrete and real (AMARAL NETO, 1989).

In any case, what is fundamental here is the explanation that individual autonomy, whatever it is treated in any way, is supported by law and, therefore, must be taken as a guiding principle.

Furthermore, given the autonomy and the possibility of each individual to determine themselves in certain situations, there is the so-called right to one's own body, which would be translated based on the values of the human personality, according to the analysis below.

# 2.1 THE RIGHTS OF PERSONALITY: THE RIGHT OVER ONE'S OWN BODY

The human personality is the support point for prerogatives and obligations. The Federal Constitution of 1988 declared that intimacy, private

life, honor, and image are inviolable - rights considered the minimum for the listing, in law, of several others (PEREIRA, 2005).

Taking into account that the rights of the personality are tending to ensure the integral protection of the human person, it has to be that the classification must take into account the protection of physical integrity, intellectual integrity, and moral or psychic integrity.

The right to physical integrity aims to protect human health and includes the right to one's own body, living and dead. Even for terminally ill patients, there is a prerogative of refusing medical treatment due to the right to physical integrity. The right to intellectual and psychological integrity includes the right to freedom of thought, intellectual creations, privacy, and the right to personal, professional, and domestic secrecy. Furthermore, moral integrity includes the right to objective and subjective honor, in addition to protecting the right to image and identity, which reflect the idea of protecting the elements that distinguish the person, whether natural or legal, within society (GAGLIANO; PAMPLONA FILHO, 2009).

Therefore, the availability of the body itself, according to a good part of the doctrine, can be based on the personality rights of each individual, correlated to their personal dignity.

It is noteworthy here, however, that despite the right to one's own body, related to respect for personality rights, being defended under numerous perspectives, among them that related to euthanasia, the day when this will be uncontroversial seems far away. The search for the protection of assets that would be of trans individual ownership, and that would go beyond the sphere of personal discernment, with a focus on the right to life, from this point of view, should prevail. Therefore, the availability of the body itself, according to a good part of the doctrine, can be based on the personality rights of each individual, correlated to their personal dignity.

Thus, one of the theories to explain the possible prevalence of the right to life at the expense of the autonomy of the will and the right to one's own body is the one that brings the understanding about fundamental human rights, based on the vision of human dignity in its double dimension.

# 3 FUNDAMENTAL HUMAN RIGHTS: HUMAN DIGNITY IN ITS DIMENSIONS

It is necessary, at this moment, to explain, albeit succinctly, human dignity, in its double dimension, and the consequent concept of fundamental human rights.

As for the definition of human dignity, it is clear that there is great difficulty in reaching a consensus, and this difficulty comes from the vague and imprecise shapes established, as well as the polysemic nature of the famous human dignity. What happens is that it is seen as a quality inherent to all human beings, so it is usually defined as the value that identifies the human being as such, which does not bring great contributions to define it legally what is the scope of the protection of dignity (SARLET, 2005).

Even so, there is no doubt about the real existence of the value treated here, although there is, as it were, a certain skepticism on the part of some regarding the legal conception of dignity (SARLET, 2005).

Despite this, the focus of study here is related to the double dimension of human dignity. For the explanation of the subject, it starts from the understanding made by Narciso Leandro Xavier Baez.

According to that understanding, human dignity could be divided into two levels of analysis. The first level, entitled the basic dimension, would include Kant's theory. At such a level, one would find the essential legal assets for human existence, which would prevent the human being from becoming something. The second level of analysis, or cultural dimension, would encompass the theories of Benedetto Croce and Pérez-Luño, and it would include values that vary in time and space and which aim to meet the social demands of each era, in each society, according to the economic, political, and cultural possibilities (BAEZ; ROSALEN, 2012).

In this path, dignity is innate and constitutes the nature of the human being, but it also forms culture, insofar as it is the result of the activity of generations and humanity, thus constituting the dignity of man (HÄBERLE, 2005).

Therefore, it could be concluded that human rights, as a set of ethical values, whether positive or not, aim at the protection and realization of human dignity in its basic and cultural dimensions. If they aim to protect the basic dimension of human dignity, therefore, fundamental human rights will be considered (BAEZ; ROSALEN, 2012).

In this north, the basic dimension of human dignity is materialized by a set of rights that prevent human beings from being treated as a thing and represents a person's quality, which demands respect for their life, their freedom, and their physical integrity and moral (SARLET, 2005).

In this way, the violation of the basic dimension of human dignity is characterized by a situation in which the human being is reified, ceasing to be an end in itself, reducing to an object or an instrument of satisfaction, and subjugation of the will of others. Here, human dignity is expressed as a limit to the State and society since it is an insusceptible attribute of reduction, legal or cultural (BAEZ; ROSALEN, 2012).

Therefore, the human rights that tend to protect and accomplish human dignity in its basic dimension would be the so-called fundamental human rights, those that prevent individuals from being taken as objects, guaranteeing them, in fact, the status of subjects of rights, regardless of the culture in which they are inserted (BAEZ, 2011).

That is the case of the fundamental human right to life, since life, without the slightest shadow of a doubt, is a basic and essential legal asset for human existence, which prevents the individual's objectification, and quarantees their position as the subject of rights.

# 4 THE FUNDAMENTAL HUMAN RIGHT TO LIFE: PONDERATIONS

The right to life has always been highlighted in the study of human rights, and for what reason not to say, fundamental human rights, as it is considered essential and a priority. This right was recognized as a fundamental right by the Constitution of the Federative Republic of Brazil, in its article 5, caput (BRAZIL, 1988).

The right to life indeed encompasses the right not to be deprived of life, and consequently the right to remain alive, as well as the right to have a decent life.

In that direction, as an object of law in its constitutional aspect, it is considered not only the biological meaning of life but its more comprehensive biographical meaning (SILVA, 2010).

But, from what moment does life begin, and, deeply, when does legal protection have an impact on that life, at least when it comes to the national legal system?

As for the beginning of life, several theories seek to establish defining parameters.

The genetic view stands out, which advocates the starting of the human life with fertilization; in the embryological view, the beginning of life occurs from the third week of pregnancy, when human individuality is established; in neurological perception, life begins when the fetus starts to show brain activity; in the ecological view, life is from the moment when the human being can live outside the maternal womb. There is also the metabolic view, which ensures that the discussion about when life begins is irrelevant, since everything is just a continuous process, the sperm and egg being as alive as anyone (MONTAL, 2010).

In the legal-philosophical view of the beginning of human life, two currents try to explain when the human being has full protection: the natalist theory, for which only after the birth with life does legal protections apply, and the conception theory, for which rights exist from conception. The most accurate theory would be the one that explains the beginning of human life from conception when there must already be legal protection (MONTAL, 2010).

Furthermore, according to the system adopted by the Brazilian Civil Code, birth with life is the starting point of personality (the moment when the fetus separates from the mother, undoing the biological unit previously presented, and breathes, even if it perishes afterward) (BRAZIL, 2002). However, the rights of the unborn child are respected, from conception, when the formation of the new being begins (GONÇALVES, 2011).

It should be noted that, in the constitutional sense, life is a process that takes place with conception, changes, and progresses, maintaining its identity until death. Human life, which is the object of the right enshrined in Article 5, caput, of the Federal Constitution, constitutes the primary source of all other legal assets (SILVA, 2010).

As explained, the right to life deserves protection against acts aimed at mitigating its realization.

In this sense, some say that the protectionist way in which the right to life is seen from the premise that it is something sacred and, therefore, inviolable (DWORKIN, 2003).

Despite this, life must be protected against everything and everyone, as it is the object of a very personal right, with respect for it and other related rights an absolute duty erga omnes, to which no one is lawful to transgress. So it would be even if there was no constitutional protection to the right to life since this is due to the norm of natural law, which in turn is a phenomenon of positive law, based on a concept whose maxim is the Universal Declaration of Human Rights, a fruit conceived for the collective consciousness of civilized humanity (DINIZ, 2001).

Thus, life would be able to condition all other personality rights, such as freedom, equality, security, and property (SANTORO, 2010).

Still, if the basic dimension of human dignity is analyzed, the right to life would be a basic, supreme value, being, therefore, a fundamental human right (BAEZ; ROSALEN, 2012). In this step, since it is part of the set of rights inherent to one's dignity, unmoved by mitigation, under penalty of human being's objectification and violation of one's status as a subject of rights.

Therefore, it is common ground that life is the most closely protected legal asset. Usually, from this conception, some questions related to the violation of such rights are raised. The question lies in the doubt about the existence of some compelling reason that could enable the legal asset of life to be discussed.

#### **5 DEATH WITH PERSONAL DIGNITY**

Personal dignity is the condition considered by each individual to live with dignity, regardless of generic concepts about what the dignity of the human would be and, it seems, it will not keep, at least soon, with a consensus, that is, about the difficulty of its definition (MEIRELES, 2009).

Nevertheless, the concept of what it would be like to die with dignity is necessary. Death is a process inherent in the vital process. In this way,

death with dignity would occur at a time chosen by the holder of the life, autonomously, and through the preservation of their dignity. In this sense, a dignified death would be if it corresponded to what the terminal patient would understand by being dignifying for their own life, according to the analysis below.

#### 5.1 DYING DENTELY: REQUIRED CONCEPT

Very little is known about death. However, despite that, the only certainty is that it is inevitable, and that is precisely the reason why the criterion of dignified and humanized death is sought. Namely, the event of death already seems to be something terrifying, and the attempt to make it a moment somewhat more comfortable, avoiding exacerbated suffering, is so to speak, the argument for the search for the dignification of that moment so full of fears and insecurities by its very nature. To speak of a dignified death is to talk about respect for the dignity of the terminally ill person's life.

In fact, everyone has the right to live with dignity, and in the same way, those people have the right to have their dignity respected throughout their lives, they also deserve to have it respected, at the moment when the crucial time for the decision between dignified and less painful death, and the prolonged one, comes with a huge load of pain and suffering. The discussion about euthanasia, therefore, is a prerequisite for understanding dignified death (GIOSTRI, 2006).

Every day, around the world, rational people ask that they be allowed to die, sometimes begging other people to suppress their lives. Some of them are already in the process of dying, in a state of unbearable suffering, and others prefer to die because they no longer want to stay alive in the only way they have left. Finally, there are cases in which relatives ask permission

to end the life of a family member, as the patient in question is already in an irreversible vegetative stage (DWORKIN, 2003).

It cannot be ignored that dignified death is defended, but it is not a premise accepted by the unanimity of jurists, doctrines, and common sense, as several interests conflict in its realization, and finding a legally accepted solution to those conflicts is a question very difficult to solve.

Those who defend dignified death state that refusing to do a certain therapeutic procedure does not mean refusing to live. The individual, based on their worldview, makes their choice, bearing the possible and probable risks. It is up to the therapist to adopt procedures that enable well-being applicable to the case. If the patient dies, there is no need to question, as death is part of the life process itself. The patient, autonomous, so decided, bearing the possibility of death, and thus understood to accomplish a dignified death, framed in their concept of a dignified life. To die with dignity is to accept death as an inexorable fact of life itself (FABRIZ, 2003).

In this way, the preservation of life only by the privilege of its biological dimension, neglecting the quality to be provided to the individual, can no longer be considered nowadays, according to that understanding. Prolonged life is justifiable if it brings some benefit and as long as it does not hurt the dignity of living and dying, otherwise dignified death must be accepted, as it respects all other constitutive dimensions of an individual, and not just the biological issue ( $S\acute{A}$ , 2001).

Death must be faced, then, as being an essential part of life and something that provides it with meaning, not allowing it to fall into an innocuous and unpleasant continuity. (CABETTE, 2009).

As an open value legal category, personal dignity (and the issue of dignified death) must be faced on a case-by-case basis so that it is up to the

terminal patient to define what would be a dignified death for the patient to put it into practice (MÖLLER, 2007).

It is noted that the concept of a dignified death is linked to the altruistic and humanitarian issue of facing the death process, in keeping with the way of preserving the terminal patient, providing them with a peaceful and humanized death, when there is no possibility of maintenance of their life, with dignity.

Then, from the analysis of dignified death, the need to elucidate some related concepts becomes evident, which leads to a greater theoretical foundation on the theme.

# 6 CONCEPTUAL APPROACHES: DISTINCTIONS BETWEEN DOCTRINE CATEGORIES

The term euthanasia appeared in the 17th century, in 1623, by the creation of the English philosopher Francis Bacon, in his work *Historia vitae et Mortis*, and it originates from the Greek expressions *eu* (good) and *Thanatos* (death) so that it has its meaning linked "good death" (SÁ, 2001).

Euthanasia is understood as the act of shortening the life of a terminal patient to minimize the suffering arising from the situation in which they find themself. Euthanasia is conceptualized as a sweet, peaceful, or merciful death. The practice implies granting the immediate end of life to those who suffer from an incurable disease and who, for that reason, prefer this type of death to prolong their torment by endless periods of suffering. They prefer death to wait for it to be impregnated with pain (VIEIRA, 2003).

On the other hand, dysthanasia occurs with medical behavior where there is an excessive fight to keep the patient alive, a tenacity translated into therapeutic obstinacy, uselessly delaying the patient's natural death, through the use of unjustifiable therapeutic methods, in cases of imminent and irreversible death. Dysthanasia is dedicated to prolonging the maximum amount of human life by fighting death as if it were the great and last enemy to overcome (GIOSTRI, 2006).

Orthothanasia is seen by its defenders as the correct death, for it occurs naturally and without too much suffering, practiced only palliative acts, instead of painful treatments when the cure is impossible. The patient's death is considered a natural fact of the biological cycle of life, for the simple reason that their death was not intentionally sought, neither by themself nor by the doctor. Death is, as explained, only the biological cycle being completed (GIOSTRI, 2006).

To perform orthothanasia, it is essential that the patient's mortal process begins and that there is no possibility of healing or salvation. Given the existence of the possibility of the patient being saved small, the medical professional must continue with the treatment, and in any case, must cease to consider them useless (SANTORO, 2010).

Misthanasia is social euthanasia. It is death that occurred ahead of time and is not considered good or even painless. The term was introduced by Leonard Martin, who considered the use of the word euthanasia to be inappropriate for cases such as those that characterize it (SANTORO, 2010).

Thus, misthanasia is the unfortunate death that occurred within the universe of the poor. Hence to be seen as social euthanasia (JUNGES, 1999).

Assisted suicide, also known as self-euthanasia, is characterized by being a kind of euthanasia performed by oneself, without the direct intervention of a third party, even though there is the participation of other people, who provide material or moral assistance to perform the act.

There is a difference between active euthanasia and assisted suicide. In the latter, the patient is assisted for death, and all acts made to accelerate the death are performed by them, as in the first, there is a need for a third person to act to accelerate the patient's death (DINIZ, 2007).

Nowadays, the World Medical Association understands that the doctor is ethically prohibited from helping the patient die, either by practicing behaviors that cause the death or even by assisting. On the other hand, the doctor's respect for the patient who refuses to undergo treatment is considered ethical conduct by the same entity, taking into account the principle of autonomy (SANTORO, 2010).

At this point, given everything explained so far, it is necessary to ask the question about the possibility of a dignified death, based on the autonomy of the will. In other words, should the right to life prevail, or is there a possibility that, based on the right of self-determination and the right to one's own body, one opts for early death, but free of all the burden of pain and suffering?

# 7 DYING WITH DIGNITY: THE COLLISION BETWEEN THE FUNDAMENTAL HUMAN RIGHT TO LIFE AND THE AUTONOMY OF WILL

The discussion emanating from the collision between the right to life and the autonomy of the will is, in fact, quite heated. While for some, the right to life is an absolute priority, there is no need to talk about mitigation, in any case, even because it is a fundamental human right, for others, the autonomy of the will, and more deeply, the right to the individual's self-determination should prevail, according to the case analyzed. The struggle covers not only the issue of dignified death or euthanasia but also cases such as abortion, since, in a broader analysis, those cases would be facets of the same problem. The study is fixed, however, on the question related to the issue of dying with dignity.

The advocates of euthanasia argue that the autonomy of the terminal patient should be respected in the face of death so that this issue raises numerous controversies due to the supreme value attributed to the fundamental human right to life.

On the one hand, on the issue under analysis from the perspective of law as integrity, it is explained that people should be concerned with respecting the patient's autonomy, their fundamental interests, and the intrinsic value or sanctity of their life. However, there is a risk of not understanding any of those issues or not realizing whether or not they are favorable to euthanasia in a given situation until it is better understood why some people try to stay biologically alive as long as they can, including in tragic circumstances, and why others, under the same conditions, prefer death as soon as they can die (DWORKIN, 2003).

Concerning fundamental interests, many of the people who are against euthanasia are for paternalistic reasons, claiming that even though autonomy exists, the option for death would hurt the fundamental interests of the one who opted. However, there is a question about the fact that, eventually, it is not better for the fundamental interests of the patient to die instead to continue in the survival in which one finds oneself. It is also questioned why people worry so much about death when there is nothing more to be experienced than terrible pain and suffering, and why they are not indifferent to what can happen in such a circumstance (DWORKIN, 2003).

Thus, autonomy as a bioethical principle is justified as a democratic principle, in which the individual's free will and consent must appear as preponderant factors since they are directly linked to personal dignity (FABRIZ, 2003).

On the other hand, the right to autonomy finds limits. Everyone has the freedom to determine the course of their lives, but this does not necessarily mean that one can abdicate it (FABRIZ, 2003).

Yet, even though not even the right to life can be considered absolute, the contempt for human life, even in more adverse circumstances, seems suspect, behold, the preservation of life in a strict way composes, so to speak, the protection of human dignity. It should be noted that the right to life is an instrument that allows for the realization of dignity, and its denial would inevitably lead to the absence of the subject of dignity (BARROSO; MARTEL, 2010).

Thus, if the case is analyzed under the aspect of the dimensions of dignity, previously detailed, it is opportune to mention that life is part of the basic dimension considered, consequently, a fundamental human right.

If therefore, life is a fundamental human right, deserving respect under penalty of injury to the individual's rights subject status, the autonomy of the will, which is not unlimited, necessarily, in this case, should be mitigated, so to speak, so that preserve the greater good, life.

The incessant questioning remains. Life is a supreme value, and that is because it is a fundamental human right according to the theory presented elsewhere. On the other hand, some ensure that life only deserves to be respected when it is lived according to the values of human dignity and autonomy. Hence the heated conflict between the defenders of life and those who seek human autonomy through dignified death.

#### 8 CONCLUSION

The controversy on which this article is based has been discussed since the beginning and, despite that, its end seems to be far away. Euthanasia, under the name of dignified death, is vehemently defended and repudiated with the same force. In the study, we sought to analyze the focus of human dignity in its double dimension: basic and cultural, trying to locate the right to live in one of these dimensions, then to verify the possibility or not of the option for euthanasia based on the autonomy of the will.

Although this theory is investigated, it is necessary to clarify that it is not the only one, and there is no lack of logical reasons to take into account the arguments brought by those who believe that death must be an autonomous, dignified, and humanized event.

In this north, there are strong arguments in both positions, one that invokes respect for life and the other that strives for the right to a dignified death.

In the foreground, if the theory of human dignity is considered in its double dimension, it becomes imperative to convince oneself that the right to life is a fundamental human right, as it is part of the basic dimension of human dignity.

Thus, if the right to life is a fundamental human right, it must be valued, under penalty of an affront to one's dignity. If not respected, one would be disrespecting a right that goes beyond the individual sphere of choice, a transindividual right. From this point of view, the autonomy of the will, which is not unlimited, must give space for the greater good of life to be preserved.

On the other hand, defenders of dignified death point out that in a situation of pressing death, the self-determination of the holder of life must be respected, in the sense that they decide the moment when they wish to die, in a peaceful and humanized way, without pain or suffering, preserving their dignity. Under this approach, death is already certain, leaving only the choice between dying with dignity and dying without dignity.

In this way, here the opposition does not necessarily lie in the choice between life or death, but between the existence or not of the right to choose, in life, the best time and the best way to die, with dignity, as death is already an inevitable fact, therefore, it is not an option. The option would be given only concerning dying with dignity or without dignity, with all sorts of suffering and physical degradation.

Finally, it is possible to come to the understanding that, despite the recurring theme, its approach becomes essential. With the study carried out, what can be denoted is that, if taken into account the theory of the double dimension of dignity, there is no need to talk about euthanasia because autonomy must, under this point of view, give way to the protection of life, which is part of dignity in its basic dimension, considered, therefore, a fundamental human right, which would prevail in the cases in question. However, the other point of this discussion also presents strong arguments and, considering the case from this perspective, it is impossible not to question it, since, once the death is certain and urgent, the search for dignity in dying is what remains, and, so to speak, respecting the autonomy of each individual to choose dignified death, which occurred at the right time, and with due assistance, would be to respect the very life - worthy - of that same individual, considering, then, death as an inherent fact vital process.

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# PERSONALITY RIGHTS IN THE SEARCH FOR THE DIGNITY OF LIVING AND DYING: THE RIGHT TO DEATH (DIGNIFIED) AS A COROLLARY OF THE RIGHT TO LIFE (DIGNIFIED)

#### **ABSTRACT**

This article aims to analyze whether personality rights, primarily the right to one's own body, the right to psychophysical integrity, and, strongly, the right to a dignified life, can support the right to a dignified death, embodied in anticipating death in terminally ill patients. For that, qualitative exploratory-explanatory bibliographic research was carried out, using the hypothetical-deductive method. The conclusion reached is that, although the right to life should be preserved, it should be as long as it is dignified, and, since (dignified) death is part of the (dignified) life process, it should not be promptly rejected as it preserves the personality rights.

Keywords: personality rights; life with dignity; death with dignity.

#### 1 INTRODUCTION

The main subject of this study is the controversy emanating from a possible right to death with dignity, carried out with the support on the protection of some of the rights proper to the individual's personality, an extremely important subject, and even quite conflicting, as it reveals an eventual conflict between fundamental rights.

The agenda is justified because such an analysis is undeniably essential in the sphere of the study of fundamental rights, as it denotes situations covered by the protection intended by them, and it should also be noted that the assessment of personality rights is extremely current.

In the same way, the interdisciplinarity of the topic concerning dignified death demonstrates its seriousness and currentness. It is well known that the subject generates controversies far beyond legal science. Furthermore, the problem involves moral, ethical, and philosophical issues, as well as religious, medical, socio-cultural, and political aspects.

The problem of the study is based, then, on the following question: can the rights of the personality, primarily the right to one's own body, the right to psychophysical integrity, and, deeply, the right to life with dignity, support dignified death sustained in anticipating the death of terminally ill patients?

The aim, in general, is to study the personality rights and the possibility that their protection serves as a basis for the search for the dignity of living and dying, presenting dignified death as something inherent to the vital process itself, in insofar as, under this argument, dying is an act of life, the last act of life.

Specifically, the aim is to study the rights proper to the personality first, then to analyze the right over the body as a right of the personality, supported by rights to privacy and personal identity, and, finally, to seek understanding about the protection of personality rights as a scope for the realization of a dignified death.

Therefore, the study will be systematized so that, in a first moment, the analysis turns to the study of personality rights in a theoretical perspective, after, the right to the body itself will be verified and, finally, the rights inherent to the personality, such as the right to a dignified life, the right over one's own

body, and the right to psychophysical integrity, will be glimpsed as possible paradigms for achieving the anticipation of death, or simply, dignified death.

Regarding the methodological aspect, the research is based on technical, rational, and systematic procedures, with the purpose of a scientific basis, providing logical foundations for the investigation. Finally, it is an exploratory-explanatory, qualitative bibliographic collection research, in which the hypothetical-deductive method is used, and in which it is intended, based on hypotheses, to explore and describe the subject in question, revealing the possible solutions to the conflict presented, without, however, exhausting the theme.

# 2 PERSONALITY RIGHTS: A BRIEF THEORETICAL UNDERSTANDING

Today, more than ever, there is talk of personal rights, since the valorization of the human being has been increasingly sought, to the detriment of the uniquely patrimonialism conception of private law, so that today people concentrate on top of the protection of the legal system.

Thus, initially, it is reported that man's personality can position them as an autonomous being, assigning them the dimension of a moral nature. At the legal level, personality is the set of faculties and rights in a state of potentiality, which grants human beings the ability to have rights and obligations, according to Lima (1955).

As Venosa (2011) explains, very personal rights are imposed on immaterial or intangible assets. The Federal Constitution, moreover, lists a series of those individual rights and guarantees in the 5th article. They are, therefore, fundamental private rights, which need to be respected as a minimum content to allow the existence and coexistence of human beings.

An exponent in the matter, Bittar (1989), clarifies that personality rights tend to safeguard the human being, as a person, and are the result of the protection given to the famous "dignity of the human person". In this form, they tend to reach legal provisions on the right to the body and privacy, being essential to human dignity, even though their theory is recent and is not exactly solidified, with divergences, especially concerning their generality and extension.

Likewise, when analyzing the protection provided by the personality right, it appears that it seeks to regulate the protection of the attributes proper to the individuation of a person, seeks the protection of intimate aspects of the individual - taken in oneself or as an individualized entity in society - or aspects arising from their interaction or projection in that same society, according to Bittar (1989). Those rights are intended to ensure the concrete protection of the individual.

Related to that, as reported by Freitas and Baez (2014), the real individual is not characterized as an abstraction but coexists in society and assimilates values with which they identify. However, full correspondence between personal and community values will not always be possible. Thus, to claim that the "concrete individual" is the result of community values would be risky. On the contrary, there would be a need to protect them from interference by the community, even if such invasions of disrespect came from living in liberation groups and social movements with which they had a pertinent relationship.

In the same direction, for Bittar (1989), the personality rights safeguard the protection of intimate aspects of the individual, or aspects originated from their interaction or projection in society. The personal psychic sphere protection would be included in the personality rights. Likewise, the attributes of the physical body protection, such as the right to one's own body or separate parts of it, is also included in the rights proper to the personality.

It is necessary to point out that, despite the current rights inherent to human personality, they are carefully safeguarded, which has not always been the case.

Regarding the evolution of those rights, Sá (2000) reports that the legal protection of personality is attributed by traditional doctrine to the Roman people. At the time, the terminology "personality" referred only to individuals who had three statuses: status libertatis, status civitatis, and status familiae, which were then the assumptions of capacity. The person would necessarily need to combine those attributes: to be free and not a slave, to be a Roman citizen, and also to be a patriarch of the family, the pater familias.

According to the author, even then, the current protective forms of the individual personality were unknown. Guardianship, then, was given through isolated attitudes.

Thus, for protection in the face of *iniuria*, an offense concerning personal physical injuries, which suffered, after numerous conceptual extensions, the procedural remedy, according to Sá (2000), was actio *iniuriarum*. Then there was Lex Cornelia, promulgated in 81 BC, aimed at protecting the homestead. Lex Aquilia emerged to make possible the action to defend physical integrity, and Lex Fabia appeared as a procedural means for the defense of rights inherent to personality.

Therefore, it can be said that, although not presenting the same intensity with which it is studied today, the individual personality already had several tutelary manifestations in an initial stage, so to speak. At that time, there was no need for the individualistic focus under which the human person is analyzed today, according to Sá (2000).

Indeed, as Tepedino (2008) well reflects, personality rights were not treated by Roman law in the same way as is known today, although their incipient proposal is attributed to them. The category of personality rights

as it is regarded today was recently built, as the result of the Germanic and French doctrinal elaborations, from the second half of the 19th century, so that, currently, under the name of personality rights, are comprised the rights that refer to the protection of the human person, considered essential to their dignity, as well as to their integrity.

Consequently, in present days, personality rights are protected by law. For those rights, the Brazilian Civil Code dedicates, on its general part, a chapter (articles 11 to 21). The chapter can be divided into norms regarding the disposition of the own body, the name, the image, and the private life.

It is essential to clarify that, even though legislation takes care of some personality expressions, the person's guardianship is not limited to them. Thus, the general clause for the human person protection of Article 1, item III, of the Federal Constitution, is inclusive (BRAZIL, 1988). That means that a subjective situation that refers to personality protection does not need to be a typical personality right to be worthy of protection, mainly because even circumstances that are not a right are worthy of equal protection. Thus, personality rights, or existential situations, are *numerus apertus* and not *numerus clausus*, as Meireles (2009) corroborates.

Still, according to the author, in the current Brazilian Civil Code, the position acquired by the "person" from the Federal Constitution of 1988 does not go unnoticed, with the discipline of the rights of the person being treated independently of his/her patrimony. There is strong protection over the so-called personality rights, which, despite being called so, are often protected before the acquisition of civilian personality and admit projections beyond the end of the same civilian personality.

In the same way, for Meireles (2009), with the constitutionalization of civil law, it is necessary to re-read the institutes of civil law from the perspective of constitutional values, especially the value of human dignity, which therefore makes it the human person diligently tutored and at the

center of the civilist discipline. Then, there is the migration of the individual to the human person, from individualism to personalism, from the abstract subject to the concrete.

Therefore, because the person is a being in itself and not just having entitlements, it reaches a fundamental level in constitutional values. People cannot be marginalized, as they once were, obtaining, without a doubt, privileged space today. That is true even for the present tutelage of the body itself, according to the analysis below.

### 3 THE RIGHT TO THE BODY AS A RIGHT TO THE PERSONALITY SUPPORTED BY RIGHTS TO PRIVACY AND PERSONAL IDENTITY

Initially, issues related to the human body, and the consequent right to it, have been considered for a long time, as discussed in Chaves (1977), although, in the past, with some thrift. Nowadays, such questions have become of paramount appreciation, given the increasingly intense search for the individual right of self-determination - in relation, even, to the body itself.

Thus, it is considered that the right to one's own body is embraced by the so-called personality rights. In this sense, Bittar Filho (1995) points out that a significant right in the human personality defense is what is recognized in terms of the body, verified in the light of the observation that it is the instrument by which people are realized in the world of facts. The body, as the author explains, has the function of allowing life and, therefore, in its entirety, it must be conserved and protected in the legal sphere.

Still, according to Bittar Filho (1995), the qualifications inherent to personality rights are integrated into this right, emphasizing the *ad vitam* character of which it is attached, accompanying the being from the

formation to the extinction of life - even though there are rights over the dead body.

It should be noted that, in matters related to the body, Article 13 of the Brazilian Civil Code points out that, except for medical requirements, the act of disposing of the body itself is prohibited when this implies a permanent decrease in physical integrity or contradicts good customs. Nevertheless, such a legal provision must be seen in the light of the Federal Constitution, given the constitutionalization of the civil law itself. Therefore, any interpretation that is made on the subject must be taking into account the general clause of protection of human dignity, as well as autonomy in existential situations. Hence the so-called "right to one's own body" is considered.

Furthermore, explaining the subject from the perspective of the right of self-determination, Gediel (2000) clarifies that, historically, the judicial treatment reserved for the body has been influenced by religious thought, since the body was seen as a divine gift and deserving of specific tutelage superior to the individual will. According to the author, this thought has gradually progressed so that in modern thought, this issue has been overcome in a form that bodily integrity has been positioned in the individual's autonomy field.

Hence, "the right to one's own body", emphasizing that the body must attend to the personal fulfillment of each individual and not to the interests of entities such as the church, the state, or even the family, according to Schreiber (2013).

In fact, self-determination over one's own body constitutes, unequivocally, the exercise of freedom, enshrined in the Constitutions, since the advent of the Modern State in the 18th century, and is expressly guaranteed by the Federal Constitution, in its article 5, item II, according to Freitas and Pezzella (2013).

Also, talking about the right of self-determination of one's own body, in this same link, is talking about the right to privacy and personal identity, according to the authors. Note that the body is part of the human being's identity and is the instrument by which they understand themselves in the world

It is necessary, then, to conceive the self-determination of one's own body as a guide for the realization of this personal identity, what Habermas (2010), in his work "The Future of Human Nature", brilliantly calls the right to self-understanding, insofar as the how each one understands themself in the world encompasses the corporal dimension.

Just for the sake of clarification, in terms of the national legal system, it should be noted that the right to personal identity is also covered by the protection granted to the personality (as well as the right to privacy), despite not being expressly exposed in the Brazilian Civil Code, as understood by the protection emanating from the general clause of protection of human dignity, consecrated in article 1, item III, of the Federal Constitution, according to Schreiber (2013), and, as it is known, the role of personality rights in the Civil Code is not *numerus clausus*. As mentioned, a subjective situation that refers to personality protection does not need to be a right detailed in the Civil Code to be worthy of protection.

So, going back to explaining the right to the body, according to Chaves (1994), the subject of the right at your disposal is not exactly new. It has been gradually moving from the scope of speculation to a concrete practice, which therefore requires the intervention of legal rules. Thus, the mere factual situation, indifferent to the law at a given time, assumes legal relevance, precisely when the community attributes social transcendence.

According to the teachings of Venosa (2011), it is already established that the general principle laid down in the Civil Code stipulates that no one can be constrained to the deprivation of their own body against their will. In

this sense, there is no prerogative to hurt the sovereignty that each being has over itself, and that includes the physical body.

Furthermore, for Cohen (2012), each is its body, so that the body is intrinsically part of human individuality. In this way, the author reports that all people are embodied individuals, that is, the person's body is not extrinsic to what they are; for what is part of their dignity. Identities and individualities are intrinsically involved with bodies, and what is made of them since the body is the person's way of being in the world and the question of the inviolability of the personality through the body's control is essential to any notion of freedom.

From the same vertex, Freitas and Baez (2014) emphasize the importance of the term *embodiment*, meaningful of the composition, in the sense of the body itself as a substrate of its own personal identity. As with the other dimensions of privacy, the integrity of the body is essential for the understanding of decision-making autonomy, and consequently, for the formation of one's own personal identity.

It is even on those bases, and with the dimensions identified in the Federal Constitution of 1988 that Freitas and Pezzella (2013) propose the resumption of privacy to redesign its content, to promote adequate protection for the body self-determination, ensuring the personal dignity of each human being.

Look at the visceral link between the right of self-determination over one's own body and the right to privacy and personal identity. Concerning the first, it can also be added that respecting the individual's personal privacy means respecting their right to self-determine bodily.

Goffman (1971) understands that the feeling of control over one's own body is indispensable for a person's integral perception of themself, which also occurs for their own personal self-confidence. Control over one's own body is fundamental to safeguard the subject's personal dignity.

In that way, the possibility constantly arises that the right of self-determination over one's own body, supported by rights to privacy and personal identity, can work as a support for the idealization of a peaceful and humanized death, where that is giving priority to safeguarding human dignity. The right to psychophysical integrity, the right to live as long as they are dignified are grounded arguments in the defense of the right to die. It is what is exposed ahead.

# 4 THE PROTECTION OF THE RIGHTS PROPER TO THE PERSONALITY AS A GUIDE IN THE REALIZATION OF DIGNIFIED DEATH: THE RIGHT TO A DIGNIFIED LIFE, THE RIGHT TO ONE'S OWN BODY, AND THE RIGHT TO PSYCHOPHYSICAL INTEGRITY

As outlined throughout the study, the relevance of personality rights is unquestionable, as they safeguard human beings in essential aspects and bring out human dignity. In those terms, the questioning related to the possibility that the search for the protection of those rights may lead to the achievement of the called death with dignity, or dignified death, which is a very important subject.

Note that the term "dignified death" means that death is a fraction of life, which is why the way death occurs is so important. Dying with dignity, then, is part of the process of living with dignity.

Thus, the first of the listed rights, the right to life, in a broader conception, so to speak, would encompass the right to die because dying is inherent to living, and what is sought is preserving life with dignity, respecting the option for death with dignity - humanized and autonomous - is the necessary measure.

It should be seen that, from this perspective, the preservation of life solely by biological criteria, without concern for the dignity of living, should be rejected as an argument, therefore believing that accepting death as an act of life is to preserve the terminal patient's right to a dignified life.

Even on the subject, Farias and Rosenvald (2011) clarify that there is the possibility of visualizing the search for a dignified life as an assumption of personality rights, as there is a true general clause codified in human dignity. Thus, since human dignity is a value to be fulfilled concretely, it becomes possible to conclude the existence of a right to a dignified death, just as there is a right to a dignified life.

Besides, adds Santoro (2010) that the right to a dignified life must be complemented by the right to a dignified death, with real respect for the natural course of human existence. Even because subjecting a person to therapeutic torture to give them more quantity of life, to the detriment of their quality, is shown as right conduct that transgresses their dignity, in that no one can be subjected to torture or inhuman or degrading treatment, under Article 5, item III, of the Federal Constitution.

Cabette (2009) corroborates that the right to a dignified death emanates from the right to a dignified life. In this context, dignity is preserved, in a situation of pressing death, at the moment when the rights of the physical, psychological, social, and, finally, spiritual well-being of the terminally ill are respected.

Regarding a dignified life and the acceptance of death as part of life, Fabriz (2003) prelects that whoever defends dignified death explains that refusing to do a certain therapeutic procedure does not mean refusing to live. The individual, based on their worldview, makes his choice, bearing the possible and probable risks. It is up to the therapist to choose the procedures that enable well-being applicable to the case. If the patient dies, there is no need to question, as death is part of the life process itself. The patient, autonomous, so decided, bearing the possibility of death, and thus understood

to achieve a dignified death, behold, framed in their concept of a dignified life.

To die worthily is to accept death as an inexorable fact of life itself.

It should be noted that, therefore, the very right to life, analyzed as a right of the personality and considered in the light of the protection intended by human dignity, demands for the humanization of the moment of death.

In this north, as regards the second right exposed, the right to one's own body, for Fabriz (2003), each person can only dispose of their body and their spirit to the extent necessary for their humanization, and the person himself must decide ways he understands the most suitable for both, as in the case of a very invasive treatment, which causes extreme suffering when the choice for its realization must pass through the reflection of the patient, whenever this is possible.

Such a prerogative emanates from the current autonomy conferred to individuals concerning matters of a personal nature, especially when dealing with the body of that individual. As mentioned elsewhere, bodily integrity is allocated under the field of protection of autonomy, or, better specifying, under cover of protection of the right to self-determination. Hence it is a "right to one's own body".

In the same sense, because it is also considered an inherent right to human personality, as exhaustively mentioned, the right to one's own body is a very strong prerogative and cannot be harmed under penalty of injury the personal dignity of the subject in question.

It is about issues concerning life and death that the recognition of the right to one's own body needs to emerge completely since the right to freedom of choice for the terminal patient for the best moment and the best way to die is through the right to dispose of their own body.

Still, concerning the third right, alluded to each and every human being has the right to be kept unscathed in its physical, moral, and psychological

dimensions. The right to psychophysical integrity, therefore, can ensure such security since it constitutes one of the bases of human dignity and therefore represents a significant example of what one has for personality rights.

Indeed, Neto (2004) states that when one seeks to protect the person's psychophysical integrity, obviously what is sought is protection that transcends human existence, in the sense that such protection specifically covers life, considered it from the point of view of dignity.

Fabriz (2003) corroborates that the psychophysical integrity of the human being is intertwined with their dignity so that it is possible to glimpse the protection of this right in the bodily, psychological, and moral dimensions. Such a right, therefore, aims to ensure that the individual does not suffer violations in the body or other aspects of the personality.

Schreiber (2013) adds that the Brazilian Constitution of 1988 recognizes the right to psychophysical integrity in a series of legal provisions, although there are still many paths to be pursued for the attribution of effectiveness to the physical and psychological protection of human beings. That is even the case when death is near.

Thus, in topics related to bio-law and bioethics, the right to psychophysical integrity takes on special value. Regarding the possible right to a dignified death, it could not be different, since to uselessly delay the death of a terminal patient would profoundly injure their right to physical, psychological, and moral integrity, causing intense suffering, since in a vegetative life obviously, integrity as a whole would be neglected, as Santoro well ponders (2010).

Imposing an aggressive and useless treatment in terms of cure or improvement in the clinical panorama, facing life as a duty, would, then, hurt several of the most elementary rights of the person.

Therefore, it is clear that the protection of personality rights is strongly sought in the most diverse situations. It could not be different concerning the question of the option for a dignified and humanized death, which occurred at the moment and in the manner desired by the patient, precisely because rights of unique relevance, such as those listed, are involved.

In addition to them, it is obvious that the right to autonomy of the human being's will, and, even more deeply, their right to self-determination, are issues that further corroborate the search for a humanized end of life. The rights to privacy and identity, also as rights proper to the personality, support, in the same path, extremely strong arguments in favor of dignified death.

So, even though the idealization of early death, free of a whole load of pain and suffering, is still a very controversial issue from the point of view of the national legal order, what is not questioned is the importance of preserving the exposed rights. And they, without a doubt, would be truly preserved in the realization of the right to die with dignity.

#### **5 FINAL CONSIDERATIONS**

The theme addressed in the current article is very controversial since the defense of death with dignity permeates winding paths, and the day does not seem to be near when a minimally harmonious solution to the problem will be reached, despite the efforts of been sought.

Still, the realization of death with dignity based specifically on the defense of the rights of the personality, which was intended to be considered, brings big controversy, and it is not for nothing, since a series of rights inherent to the human being is put in vogue when the possibility of its realization.

It should be noted that the purpose outlined here was not to exhaust the issue but to structure it in such a way as to bring important clarifications and seek its understanding. The analysis from the perspective of personality rights, thus, allows viewing the problem in a specific and targeted way, analyzing it from one of its various facets.

The importance of the right to psychophysical integrity is uncontroversial insofar as it proves to be essential to the very achievement of the personal dignity of human beings, and its protection includes the safety in its physical, moral, and psychological dimensions, as exposed during this work. The right to one's own body has, in the same way, taken increasingly positively astonishing proportions, in the sense that the defense for the body's self-determination has been increasingly sought after, although the issue is controversial. Furthermore, the right to life, or the right to a dignified life, has unquestionable relevance.

Likewise, the option for dignified humanitarian death, which took place at the time determined by the terminally ill, would make their self-determination shine, as well as protecting their most intimate rights inherent to their personality, such as those exposed before.

Thus, the right to life is extremely important, especially when it comes to the national legal system, in such a way that it is even part of the rights of the human personality. What is considered, however, is that the search for life cannot happen without the search for the dignity of that same life.

Equally, what can be added is that the relentless struggle for life-based solely on its biological criteria, disregarding the most elementary values and rights, such as the rights to psychophysical integrity and the body itself, in addition to the right to preserve privacy and personal identity, it should not be accepted conduct without questioning, since, with this search without measures, the injury of the listed rights occurs, a presupposition for the preservation of the individual's dignity.

What we intended to report was that, in the national legal system, the right to life is protected in an extremely forceful way, since the life of another cannot be reaped - except in very rare exceptions, as in the case of declared war, where the death penalty is allowed, or in the case of abortion, allowed in case of risk of death for the pregnant woman, rape, or, through the gestation of an anencephalic fetus (if it is taken into account that the national legislation considers life from conception), themes in which the study did not intend to go deeper. Also, there is no prerogative of the provision of that right by its owner.

Nevertheless, the study aimed to reveal rights that, likewise, are elementary to each and every human being and that, yes, deserve to be taken into account in detriment of the pure and single maintenance of human survival, suggesting a change of paradigms, including concerning national legislation to bring to light the need to preserve the autonomous decision of the terminal patient, in case they decide for early death, free from suffering and psychophysical degradation, considering that the right to die worthily does not hurt the right to life, since death is an act of life; who decides to die with dignity is not disposing of their right to life, but choosing to anticipate an imminent and inevitable act (death).

It is necessary to abandon old dogmas and face the right to live from a more humane perspective, prioritizing the dignity of that same life so that, if so, dying in a dignified manner is not conduct opposed to the protection of life.

Therefore, what is posed is that the right to life must, of course, be preserved. But, more than life, a dignified life must be sought, and as correlated in the previous lines, dying is the last act of life, so, dying with dignity must be seen as an act inherent to the process of living, with dignity, since the right to die and the right to live are faces of the same right. (Dignified) death is part of (dignified) life.

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## FROM DYSTHANASIA TO EUTHANASIA: REFLECTING THE DIGNITY OF LIVING AND DYING

#### **ABSTRACT**

This article aims to investigate the dilemmas faced in the terminal patient's death process, based on the analysis of dysthanasia, or therapeutic obstinacy, and euthanasia, or anticipation of death. It has as an issue, the confrontation of the question concerning the possibility of preserving the personal dignity of the terminally ill, at the moment when death is near, confronting the conduct related to dysthanasia and euthanasia, as a retarder and accelerator, respectively, death process. The objective, then, is mused in the reflection about the death process and the dignity of living and dying, using therapeutic obstinacy and anticipating death as opposed to conducts taken in the face of the terminal state of human life. For that, a qualitative exploratoryexplanatory bibliographic research was carried out, using the hypotheticaldeductive method. Regarding the results achieved with the research, it is argued that, although there have been long research on themes that permeate dignified death, there is still much to be thought and demystified. The conclusion reached is that both behaviors can bring problems, and dilemmas, within them. Dysthanasia, or therapeutic obstinacy, can generate excessive and unnecessary suffering for the patient who, due to the very situation in which they find themselves, already suffers and deserves to have their dignity preserved. Euthanasia, in turn, although called dignified death, cannot be taken deliberately. What should happen, then, in principle, is the search for the preservation of the terminal patient, of their dignity, with their autonomy and power of discernment being safeguarded, at such a crucial moment, if they can express them. The theme contributed to the extent that it was studied in a critical way called concepts, which, certainly, still need to be considered a lot, in the legal sphere.

Keywords: dysthanasia; therapeutic obstinacy; euthanasia; autonomy; dignity.

#### 1 INTRODUCTION

The study in question has as its central theme the discussion involving the expressions dysthanasia and euthanasia, both behaviors are taken in the death process, the first being characterized as a therapeutic obstinacy, and the second as the anticipation of death.

The study is justified, as the theme on which it is based is very controversial, and has been discussed since the most remote times, and, despite that, it is extremely targeted, even in contemporary times.

The problem of the study is based, then, on the verification of the questioning regarding the possibility of preserving the personal dignity of the terminal patient, at the moment when their death is close, confronting the conduct related to dysthanasia (therapeutic obstinacy), and euthanasia (anticipation of death).

The goal, in general, is to reflect the process of death and the dignity of living and dying, using dysthanasia and euthanasia as a source, terms that, although they seem similar, translate opposite behaviors or at best extremely different hypotheses. Also, specifically ponder about dysthanasia, euthanasia, and, afterward, confront the terms in the search for considering the existence of death with the preservation of personal dignity.

Therefore, the study will be systematized so that, first, the concept of dysthanasia, also known as therapeutic obstinacy, will be verified, after, the term euthanasia, or anticipation of death, will be analyzed, and, finally, it will be glimpsed the confrontation of the themes, to search for the understanding of the death process, with personal dignity and autonomy.

Regarding the methodological aspect, the research is based on technical, rational, and systematic procedures, with the intention of a scientific basis, providing logical foundations for the investigation. Finally, it

is a qualitative exploratory-explanatory bibliographic collection research, in which the hypothetical-deductive method is used, and in which it is intended, based on hypotheses, to explore and describe the subject in question, revealing possible solutions for the argument that is presented, without, however, exhausting the theme.

#### **2 DYSTHANASIA: THETHERAPEUTIC OBSTINATION**

The concept of dysthanasia involves the analysis of medical performance in the situation of a terminally ill patient. Diniz (2001) reiterates that, with the advances in medicine and the consequent modernization of resuscitators, it is possible to deliberately increase the survival of a terminal patient.

Thus, dysthanasia - therapeutic obstinacy or medical futility - is the patient's slow and very suffering death, due to the excessive prolongation of the death process, through ineffective treatment. Dysthanasia is not intended to prolong life but the process of death. Therefore, sometimes the use of therapeutic methods creates predictable inconveniences than benefits, the effect being more harmful than the evil to be cured.

For that reason, Namba (2009) argues that dysthanasia is the antonym of euthanasia. On the other hand, conceptualizing dysthanasia, Vieira (2003) explains that the practice consists in the conservation in life, of a patient considered to be incurable by lavishing on extraordinary care, without which, there would be no need to talk about survival.

Möller (2007) reiterates that therapeutic obstinacy on the part of doctors, when the patient is already in a terminal stage, translates into an extension of the dying process, sometimes causing more pain and suffering to the patient, who is already at the end of their life. Pessini (2001), on the

other hand, guarantees that the medical duty to prolong life at all costs does not have classical roots.

Thus, dysthanasia occurs with medical behavior in which there is an excessive struggle for the patient's life, a tenacity translated into therapeutic obstinacy, uselessly delaying the patient's natural death, through the use of unjustifiable therapeutic methods, in cases of state of imminent and irreversible death. According to Giostri (2006), dysthanasia can occur in cases where the patient, in a conscious state, or even when they are still lucid, express their desire to have their life prolonged, even through useless and painful treatments. Thus, Dysthanasia is dedicated to prolonging the maximum amount of human life by fighting death as if it were the great and last enemy to overcome.

Sá (2001) corroborates and explains that dysthanasia is dedicated to prolonging the amount of human life although, the person remains alive, the death process is delayed, which most likely that life cannot be prolonged qualitatively.

Technological advances in the medical field encourage this practice even more because, despite, on the one hand, being indispensable for the treatment of previously incurable diseases, on the other, they enable the quantitative maintenance of life, even if without quality, which does not respect the personal dignity of the terminal patient.

Likewise, Diniz (2007) reiterates that therapeutic obstinacy, or dysthanasia, is slow death with intense suffering. Technological advances have made it possible to maintain a person very sick or in a terminal stage indefinitely alive but linked to artificial support devices, such as mechanical ventilation. Dysthanasia is characterized by an excess of therapeutic measures, which imposes suffering and pain on the ill person, and in which medical actions are not able to modify the morbid condition.

Therefore, according to what is obtained, what should occur is the denial of medical conduct that goes beyond the duty to act, established in the doctor-patient relationship, and that imposes on the patient heroic measures that sometimes disrespect their right to autonomy. According to Santoro (2010), human dignity prevents the doctor from subjecting the patient to inefficient treatment, prolonging life in quantitative rather than qualitative terms.

In this path, envisioned of what is dysthanasia, or therapeutic obstinacy, the study now begins to properly analyze the conduct considered as the opposite, the euthanasia, translated into the anticipation of death, for altruistic reasons.

#### **3 EUTHANASIA: THE ANTICIPATION OF DEATH**

The word euthanasia is commonly used as a synonymous term of "good death", "merciful death", "dignified death", among other concepts.

Santoro (2010) explains that euthanasia can be understood as an act of depriving the lives of others, who are affected by incurable affection, pity, and in their interest, with the sole objective of ending their suffering and pain.

Regarding the concept attributed to euthanasia, Silva (2010) clarifies that the term has several meanings: "beautiful death", "soft death", "quiet death", without pain, without suffering. Currently, however, euthanasia is spoken intending to refer to the death that someone causes in someone else, already in an agonized or pre-agonized state, to release them from serious suffering, as a result of considered as an incurable disease, very painful, or violent.

The term euthanasia emerged in the 17th century, created by the English philosopher Francis Bacon, and originates from the Greek expressions *Eu* (good) and *Thanatos* (death) so that its meaning is linked to "good death", explains Sá (2001). Diniz (2001) corroborates by reporting

that the expression euthanasia was used for the first time in 1623, by Francis Bacon, in his work *Historia Vitae et Mortis*, in the sense of good death.

Nowadays, the expression euthanasia is used to describe the medical action that intends to shorten the life of terminally ill patients. Euthanasia is the death of a person who is suffering from illness with no prospect of improvement and is practiced by the doctor, with the consent of the individual. It is the promotion of the death of a terminally ill patient, characterized by the doctor's commissive conduct, which uses an efficient means to cause death in incurable patients and a state of extreme suffering, shortening their life, or the omissive conduct, where they don't do something that would uselessly delay the life of the terminal patient.

Furthermore, the anticipation of death in terminally ill patients has the scope of abbreviating their pain and suffering, with purely humanitarian and altruistic purposes. Euthanasia, moreover, is based, according to its defenders, mainly on the preservation of the personal dignity of those who are in a terminal, vegetative state, or affected by a very serious and incurable disease, in which death is seen as something "certain".

Vieira (2003) conceptualizes euthanasia as a sweet, peaceful, or merciful death. Thus, the practice implies granting the immediate end of life to those who suffer from an incurable disease and who, for that reason, prefer that type of death to prolong their torment for endless periods of suffering. They prefer death now, waiting for it to be impregnated with pain.

According to Junges (1999), euthanasia means the action or omission that causes the death of the terminally ill to eliminate any pain. Thus, the term euthanasia is attributed to the practice that deliberately seeks death to relieve pain.

Therefore, by understanding the understandings made, it is possible to define euthanasia as the anticipatory practice of death of patients

in the terminal stage, performed by doctors, intending to eliminate the pain and suffer faced, carried out for merciful purposes, and steeped in humanitarian sentiments.

On the subject, Möller (2007) highlights the concern of doctors and other health professionals with what would be good or bad conduct in the exercise of the profession, has long been expressed under the Codes of Ethics and other medical deontological codes, those tending to reinforce the identification of the members with the prevailing values of the profession and the institutional conformity to them, as well as to maintain the prestige of the class before society, hence the rejection of the performance of euthanasia before the medical class is still evident, despite so much being discussed.

In this way, there is a substantial perception that, despite society's mentality regarding the practice of euthanasia, to some extent, it has evolved with time, in the sense that the practice is not regarded as something eminently rejectable, in what concerns to the deontological norms, and there is also an express prohibition regarding the performance of euthanasia, or dignified death, by medical professionals, albeit for altruistic reasons, according to the analysis carried out.

Finally, on this path, after the analysis of dysthanasia and euthanasia, there is an urgent need to confront the terms in the search for an understanding of the death process and possible dignification of such an already painful moment.

#### 4 FROM DYSTHANASIA TO EUTHANASIA: THE DIGNITY IN THE DEATH PROCESS

It was studied, in the previous lines, that therapeutic obstinacy translates into real medical tenacity. The medical professional slows down the death process, insistently, even knowing that none of the adopted procedures can save or even alleviate the suffering of the terminal patient. Euthanasia, on the contrary, corresponds to the death's anticipation of the terminal patient to shorten their pain and suffering.

It is questioned, therefore, if there is a way to preserve the personal dignity of the terminally ill patient, making their death process less painful and degrading.

For many, a solution to the conflict would be the adoption of orthothanasia, which would be death in its own time.

Orthothanasia is seen by its defenders as the correct death, which occurred naturally and without too much suffering, practiced the only palliative acts when the patient's life can be no longer maintained. Namba (2009) faces orthothanasia as not extending the death process beyond what would be natural, putting, in practice, the human being as a fundamental and central value, in the view of medicine in the service of health, from conception to death. In orthothanasia, this way, it tries to promote, with the patient, a dignified and human death, at the right time, placing palliative medicine in this line.

Regarding the appearance of the name orthothanasia, Santoro (2010) adds that the term originated from the idea of Professor Jacques Roskam, from the University of Liege, in Belgium, who at the First International Congress of Gerontology, held in 1950, concluded that between shortening human life through euthanasia and prolonging it too long due to therapeutic obstinacy, there would be a correct, just death, which occurred in due time. Hence the use of the Greek terms *Orthos* (correct) and *Thanatos* (death). The creation of orthothanasia, in this way, is opposed to both euthanasia and dysthanasia, acts of shortening or prolonging life.

Furthermore, it is perceived that orthothanasia is the behavior of the doctor who, in the face of imminent and inevitable death, suspends the

performance of acts intended to prolong the patient's life and starts to give the appropriate palliative care so that they die with their dignity preserved. Giostri (2006), when conceptualizing orthothanasia, explains that the fact that the patient dies is considered a natural event of the biological cycle of life, for the simple reason that the death was not intentionally sought, neither by the patient nor by the doctor. Death is, as explained, only the biological cycle completed.

Thus, orthothanasia is consistent with the medical practice of using only palliative methods, and not those that uselessly seek to prolong the patient's life, occurring, in the same north, a death considered natural and in its time, without unnecessary artificial delays, when death is a certain and imminent event.

Orthothanasia is a procedure adopted by the Federal Council of Medicine (2012), according to the current Medical Code of Ethics, mentioned before, and Resolution 1.995 / 2012, of the same body.

Thus, there is an urgent need to observe the bioethical principle of non-maleficence, and the doctor should refrain from proceeding with conduct that causes intentional damage to the patient. The doctor must exercise their duty for the good of the patient under their care, and dysthanasia is not being good per se, it must be avoided, for it causes pain, late and suffered death, which can be prevented through the realization of purely palliative care, according to Santoro (2010).

Still, the author reports that, while euthanasia (anticipation of death due to altruistic reasons) and mysthanasia (social euthanasia, occurred due to lack of medical care, medical error, or medical malpractice) anticipate the patient's death, dysthanasia leads to a late death. Thus, they are all wrong about the moment of death, occurring before or after the hour. The defense of death that occurred in its time would undoubtedly be sought since it would happen neither in advance nor through prolonged suffering of the patient.

So, concerning dysthanasia, or therapeutic obstinacy, it is argued that ineffective treatments must be refuted. It is reiterated that this futility refers directly to treatment, and there is no need to confuse, as Pessini (2001) warns, the futility of treatment with the futility of life itself. The concept of futility, therefore, when used within ethical parameters, will serve as protection for vulnerable subjects, such as terminally ill and vegetative patients.

In the same way, what must be refuted is the exacerbated prolongation of the death process, translated into the medical obstinacy of not wanting to "lose" the patient, imposing this even greater suffering, without the slightest possibility of a cure.

The anticipation of death, in a deliberate way, also does not seem to be the solution, a careful reflection, in a coherent way, about euthanasia, must be done, before putting it into practice, even if its realization occurs through altruistic and humanitarian arguments.

Euthanasia, thus, could be the solution in preserving the well-being of the terminally ill patient, but its achievement is still marked by doubts and contradictions, in the moral or ethical, philosophical, religious, and, finally, legal, since numerous fundamental rights of the person are involved in its realization.

It seems sensible, therefore, to seek, when possible, to consider the will of the terminal patient, to preserve their autonomy at a time already so delicate by its very nature.

Regarding the terminal patient and their autonomy of the will, Dworkin (2003) has already explained with extreme propriety that people should be concerned with respecting the patient's autonomy, their fundamental interests.

Similarly, Fabriz (2003) reports that autonomy, even as a bioethical principle, is justified as a democratic principle, in which the individual's

free will and consent must appear as preponderant factors since they are directly linked to personal dignity, even though the so-called autonomy is not considered unlimited.

Hence, care should be taken to preserve the patient's dignity, avoiding imposed dogmas, seeking, whenever possible, to protect, in the same way, the autonomy of the patient's will, whether by putting it into practice orthothanasia, employing palliative care, continue with treatment, even if it is useless in terms of cure, or stop it.

Finally, in legal terms, even though different rights have clashed when an option is made, already in a terminal state of life, the preservation of the personal dignity of the human being must be the ultimate end to be sought.

#### **5 CONCLUSION**

The theme on which the study in vogue is based is controversial and has long generated clashes and divergent opinions. Issues related to the end of life and the doubt between therapeutic obstinacy and anticipation of death generate high intense conflicts.

Dysthanasia, beholden in real medical tenacity, it is not conduct that meets most elementary rights of each and every human being, even more so in a moment so full of anguish, doubts, and suffering, as is the case of terminally ill patients, since, surely, the patient's dignity would be mitigated in the extended affliction of the death process.

It should be noted that, as highlighted, dysthanasia does not exactly aim to prolong the life of the terminally ill, in qualitative terms, but to procrastinate the death process. In this way, the treatment used can generate great pain and discomfort, being, therefore, more harmful than the very disease that affects the sick human being.

Euthanasia, on the other hand, is not a conduct immune from criticism, in any sphere of understanding that one wishes to deal with, and also in the legal sphere. The apparent conflict between the right to life and the preservation of the autonomy of the terminal patient's will is only one of the several conflict biases that exist in practice.

Despite that, euthanasia, with its ultimate purpose of preservation of the inherent rights of the individual, such as one autonomy and psychophysical integrity, and, with them, the maintenance of the personal dignity of the terminal patient, providing them with a peaceful and humanized death, can be seen as a resource for cases such as those mentioned. Still, moral, ethical, philosophical, metaphysical, religious, and legal conflicts emanate from the practice.

As a possible point of balance between the conducts, orthothanasia is cited, supported by the offer of only palliative treatments, which aim to ensure the greatest possible well-being to the terminal patient when the impossibility of cure is already established.

Orthothanasia, therefore, seeks to bring a more humanized end of life to the patient, without their death being accelerated or delayed, so that it happens in its time, and, during the death process, care to ensure the least suffering possible are taken.

What can be seen is that the day is far away when the death process, with the possible actions to be taken, will be something peaceful, uncontroversial. The moment is delicate, and whoever dares to think about it should do so sparingly.

Finally, it is clear that, perhaps, one of the ways to solve the conflict on the search for the dignity of living and dying, and the consequent dignity in the death process, is the search for the preservation of the autonomy of the terminal patient's will, to take the treatment, even if there is no possibility of cure, to stop it, and/or to only have palliative care to wait for death, in the sense that their choice is accepted based on their personal beliefs and experiences. The matter, however, is not a peaceful one, and it generates, as expected, controversial and divergent opinions, all of which are, of course, educated and thought-provoking.

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# THE RIGHT TO A DIGNIFIED DEATH BASED ON THE ANALYSIS OF THE DECISION OF THE COMPLAINT OF NON-COMPLIANCE WITH THE FUNDAMENTAL PRECEPT NO. 54

#### **ABSTRACT**

The present article intends to investigate dignified death based on the arguments explained in the decision of the Non-Compliance with the Fundamental Precept No. 54, judged by the Brazilian Supreme Federal Court. It has as a problem the questioning about what are the arguments that supported the decision taken in the lawsuit, and if they can support the option for the realization of dignified death in terminally ill patients. The objective, then, is consistent with the study of the decision, investigating the relationship between the arguments used to judge it and the possibility of a dignified death based on those same arguments. For that, qualitative exploratory-explanatory bibliographic research was carried out using the inductive method. Regarding the results achieved with the study, it is argued that the elements studied are significantly powerful and, therefore, ponderable in decisions of a personal nature, as is the case at the time of death. The theme contributed to the extent that a recent decision by the Maximum Court was considered, on a matter of unparalleled importance, as well as another extremely relevant matter, concerning the right to dignified, anticipated death, free pain, and suffering. Keywords: dignified death; therapeutic anticipation of childbirth; laic state; decision-making autonomy; torture.

#### 1 INTRODUCTION

The study in question has as its central theme the analysis of the Failure to Comply with the Fundamental Precept No. 54, the main arguments

used for the claim to be upheld, correlating those arguments with the issue of a dignified death and questioning the possibility that they may serve as a basis for its realization.

For the sake of deepening, only some of the topics considered in the decision were analyzed, which does not mean that the others are less important but reports a better delimitation of the content under analysis. Moreover, it is emphasized that the decision was not unanimous, and there are, therefore, opposite views to those listed in this article, even from the Supreme Federal Court ministers.

The study is justified, therefore, both themes under comment, the issue of early delivery in cases of fetuses with anencephaly and the matter of death with dignity, are notably current, controversial issues that deserve the right of the law and space of study in legal science. Even though there has already been a decision by the Supreme Federal Court concerning cases of anencephaly, the issue is still controversial. Furthermore, the possibility of anticipating death in terminally ill patients, based on respect for their dignity, is an extremely important and truly controversial agenda, with significant arguments, both favorable and contrary, and in all areas of knowledge that they seek their explanation or at least their understanding.

The study's problem is based on the following question: What are the arguments that supported the decision taken in the Statement of Non-Compliance with the Fundamental Precept No. 54, and could they sustain the option for the realization of dignified death in terminally ill patients?

The objective is, in general, to study the decision mentioned before, ascertaining the existing correlation between the arguments used to judge it and the possibility of searching for the realization of a dignified death based on those same arguments. Specifically, to consider, at first, the litigation that is being dealt with, then, some of the arguments that served as a guide for the decision, and, finally, the correlation between those arguments and the

right to a dignified death, in the sense that they may serve as a scope for the struggle in favor of its realization.

To this end, the study will be systematized so that, first, a brief explanation will be made about the Statement of the Non-compliance with the Fundamental Precept No. 54, in which it was decided that the interpretation according to which the termination of an anencephalic fetus is unconstitutional it is conduct typified in articles 124, 126 and 128, items I and II, of the Penal Code. Then, the study will focus on the analysis of some of the elements that supported the votes in favor of the validity of the request in the lawsuit, and, finally, the right to die with dignity and the possibility that the arguments that underpinned the decision of the Arguition of noncompliance with the fundamental precept in vogue will serve as a guide for its implementation.

With regard specifically to the methodological aspect, the research is based on technical, rational, and systematic procedures, with the purpose of a scientific basis, providing logical foundations for the investigation. Finally, it is a qualitative, exploratory-explanatory bibliographic collection research, in which the inductive method is used, and in which it is intended, based on hypotheses, to explore and describe the subject in question, revealing the possible solutions to the conflict that presents itself, without, however, exhausting the theme.

## 2 STATEMENT OF NON-COMPLIANCE WITH FUNDAMENTAL PRECEPT NO. 54: A BRIEF INTRODUCTION

The Statement of Non-compliance with the Fundamental Precept No. 54, which is intended to be analyzed, was formalized by the National Confederation of Health Workers, on July 17, 2004, before the Federal

Supreme Court. The entity was represented by the then-lawyer and today Minister of the Court, Luís Roberto Barroso. From the view of admissibility, the fundamental precepts established by articles 1, item III - the dignity of the human person -, 5, item II - the principle of legality, freedom, and autonomy of the will -, 6, caput, and 196 - right to health -, all of them from the Brazilian Federal Constitution, and, as an act of the Public Power that caused the injury, the normative set present in articles 124, 126, caput, and 128, items I and II, of the Penal Code - Decree-Law n. 2.848, of December 7, 1940 (BRAZIL, 1940).

Furthermore, it was alleged that only the fetus with extrauterine life capacity could be a passive subject of the crime of abortion and that, in the present case, what is intended is the therapeutic anticipation of childbirth, which does not constitute abortion, since to characterize as an abortion, potential extrauterine life is needed, and it is well known that in the anencephalic fetus this does not happen.

According to the rapporteur of the case, Minister Marco Aurélio Mello, the defendant at the beginning was the declaration of unconstitutionality, effective for all and binding effect, of the interpretation of articles 124, 126 and 128, items I and II, of the Penal Code, which prevents the therapeutic anticipation of childbirth in cases of pregnancy of anencephalic fetus, previously diagnosed by a qualified professional. We sought to recognize the pregnant woman's right to submit to the procedure without having to present judicial authorization or any other form of permission from the State.

Minister Marco Aurélio Mello emphasized what the defendant alluded to in the sense that the proclamation of abstract unconstitutionality of criminal types was not postulated, which would remove them from the legal system. It was argued, however, that the statements were interpreted following the Constitution. The Supreme Federal Court, therefore, did not examine the decriminalization of abortion, not least because abortion and the therapeutic

anticipation of childbirth are not confused, according to what was previously envisioned.

In short, after a long period of processing, there was a definitive decision on the agenda on April 11 and 12, 2012. It was then decided to uphold the request contained in the lawsuit, to declare the interpretation unconstitutional according to which termination of pregnancy of a fetus with anencephaly is a behavior typified by the normative set of articles 124, 126, and 128, items I and II, of the Penal Code, by the majority of votes, and according to the vote of the case rapporteur, Minister Marco Aurélio Mello, in a session chaired by then Minister Cezar Peluso.

The Federal Council of Medicine (2012), in the face of such a decision by the Maximum Court, approved the Resolution No. 1.989/2012 to regulate the practice of therapeutic anticipation of childbirth before the medical profession, providing for the diagnosis of anencephaly.

Thus, according to the provisions of Article 1 of the aforementioned resolution, in the event of an unequivocal diagnosis of anencephaly, the doctor may, at the request of the pregnant woman, regardless of authorization by the State, terminate the pregnancy.

However, the decision rests solely with the woman, who can maintain the pregnancy, interrupt it immediately, regardless of the time, or postpone the decision to another time, according to article 3,  $\S$  2, items I and II.

It is clear, in resolution 1.989/2012, the respect for the pregnant woman's autonomy, in the sense that the decision is theirs, regardless of any pressure from the doctor or anyone else.

Well then. There was an extensive discussion of the therapeutic anticipation of childbirth in the case of fetuses with anencephaly. But, what is anencephaly?

In a simplified way, as reported by Minister Marco Aurélio Mello, in his vote, it can be said that anencephaly is a malformation of the fetal neural tube, where there is a partial absence of the brain and skull, resulting from that defect, in the period embryonic formation.

José Aristodemo Pinotti (2004) corroborates by explaining that anencephaly results from the failure to close the neural tube, which results from the interaction between genetic and environmental factors during the first month of embryogenesis. It is reported that it is evident that the decrease in folic acid is related to the increased incidence of anencephaly, which explains, so to speak, its greater frequency in the less favored socioeconomic levels.

About the action in question, several authorities on the subject were heard, in a public audience, to better understand the anomaly and, therefore, to discern about the subject with greater basis and in an impartial manner. According to experts, anencephaly is entirely incompatible with extrauterine life. In fact, cases in which extrauterine survival of the anencephalic baby was believed to have been clarified by the experts. Diagnostic errors were undeniably the trigger for such doubts.

Therefore, one sees the relevance that the theme has, and, although debatable, how important was the positioning of the Supreme Federal Court, since, concerning the fetus, as it is collected, there is no potential life, and, concerning the pregnant woman, it would be painful to impose the continuation of a truly emotional and physical martyrdom.

Then, after taking a brief historical account of the Statement of Non-Compliance with Fundamental Precept No. 54, and some of the consequences of its judgment, in which the request was upheld, the decision will be analyzed in a more specific way, listing some points of analysis, for a better research design.

### 3 SOME ELEMENTS THAT SUPPORTED THE VOTES IN FAVOR OF THE VALIDITY OF THE REQUEST MADE IN THE STATEMENT OF NON-COMPLIANCE WITH FUNDAMENTAL PRECEPT NO. 54

Without a doubt, the judgment of the Fundamental Precept Failure Statement (ADPF) No. 54 was historic since it touched on a controversial aspect in the legal sphere, on a subject that also causes ambiguities in the biomedical field. There was a breakdown of paradigms when deciding on the origin of the request since moral and religious aspects were left aside in the search for the preservation of the inherent rights of women who go through this delicate situation.

Thus, to understand the agenda more specifically, comparing it, whenever possible, to the issue of dignified death, it is necessary to analyze at least some of the elements taken as parameters in the judgment of the origin of the request made in the legal case in question. Some of them were listed in the initial petition by the defendant as fundamental precepts violated.

### 3.1 THE LAIC STATE

Despite the fact that the fetus with anencephaly does not have an extrauterine life expectancy, therefore, not exactly what can be called a life, it is uncontroversial that, from the religious point of view, it must be preserved, even without the perspective of life outside the maternal womb, and this is mainly due to the sacred character attributed to human life by religiosity, especially concerning religions that consider there is life already at the junction of the egg with the sperm, as is the case with Catholicism, according to Montal (2010).

As Edison Tetsuzo Namba (2009) rightly emphasizes, life, as well granted by the divinity, or, still, by the intrinsic finalism of nature, would have a sacred status and, being that way, it could not be disposed of, even if that was the express will of its holder.

Regarding this sacredness, Ronald Dworkin (2003) has already emphasized that, in the western world, even with a separate church and state, the discussion of abortion (despite the case of the anencephalic people is not specifically about abortion) is almost always a conflict between religious sects. Practitioners of religion tend to have a strong conservative opinion on the subject. Both the ideas of the most conservative religious and those from the most liberal, who support abortions in exceptional conditions, are not based on the fact that a fetus is a person but that any human life has intrinsic and sacred value.

For the author, in religion, the simplest appeal refers to property, in the sense that life would not be of the person, but God, and granted by God to them.

Well, although the sacralized view of life remains very strong in the reality of people in general, the State cannot rely on such an argument because, as is well known, it is secular, and therefore neutral.

Thus, the Federal Constitution provides, in its article 5, item VI, that freedom of conscience and belief is inviolable, the free exercise of religious services is ensured, and, in the form of the law, the protection of places of worship and their liturgies.

In the same sense, Article 19, the item I, of the Magna Carta states that the Union, the States, the Federal District, and the Municipalities are forbidden to establish religious cults or churches, subsidize them, hinder their functioning or maintain with them or its representatives' dependency

or alliance relations, subject, in the form of the law, to public interest collaboration.

In fact, in this sense, according to Gustavo Biscaia de Lacerda (2014), the basic idea of secularism is that the State does not profess or favor - nor can do it - any religion. Secularism is opposed to the confessional State - which includes the so-called "atheist state", considering that it assumes a characteristically religious position, even if in a negative sense.

Thus, for the author, following the secularity, the State has no official doctrine, and the additional consequences ensure that citizens do not need to join churches or associations to have this *status* and even the crime of heresy does not exist (or that is, doctrines and/or interpretations that disagree and/or are contrary to the doctrine and official interpretation).

In this way, it is perceived the neutrality in the State concerning the issues raised in the study. Even in his vote, the Minister of the Supreme Federal Court, Marco Aurélio Mello, rapporteur of the case, made it clear that Brazil is a tolerant secular state, due to the constitutional provisions arranged elsewhere, in such a way that the State is not religious, nor an atheist, but that is purely neutral.

It is important to highlight that secularity and secularism are different terms. According to Francisco Faus (2005), secularism is the separation between politics (Government) and religion (Church), there is a distinction between the political and religious spheres. Thus, there is no official state religion, but it must guarantee and protect people's religious and philosophical freedom. In its turn, secularism is an ideology designed to restrict everything religious and intends to constitute itself as the only admissible one.

Therefore, taking into account the secularity that needs to be considered, the State must remain impartial about religious arguments,

including concerning issues related, for example, to abortion or the therapeutic anticipation of childbirth.

As a matter of fact, as Minister Marco Aurélio Mello emphasized, the theme of the unconstitutionality of the interpretation according to which it constitutes a crime to interrupt the pregnancy of an anencephalic fetus, does not have to be seen by religious moral guidelines, even though the hearing of religious entities, in a public hearing, when the matter is judged since they live in a Democratic State under the Law.

Thus, the minister recalls that some sectors of society consider it morally reprehensible to anticipate childbirth in cases of fetuses with anencephaly, however, this belief cannot lead to the incrimination of any conduct by women who choose such a procedure, to the detriment of taking the pregnancy forward. He reports that the Brazilian State is secular and, therefore, simply immoral issues do not deserve the gloss of the criminal law.

Note that, concerning dignified death, religious arguments, in a sense, that life is sacred and, therefore, inviolable, are often used to prevent its realization. José Roque Junges (1999) explains this sacral view and argues that, under this meander, life is God's property, conceived as untouchable, and the human being is its mere administrator.

Frequently, then, religiosity is used as a scope to invoke the impossibility of opting for the best moment to die, because, from a religious point of view, human life is God's property, and, if so, only God can establish what the hour of death for each person should be, never oneself.

However, although there must be respect for religious positions, precisely because Brazil is a Secular State, concerning state decisions, the religious arguments mentioned must also be refuted because of the asserted state impartiality.

### 3.2 DECISION-MAKING AUTONOMY, SELF-DETERMINATION OF ONE'S OWN BODY, AND PERSONAL PRIVACY

In the decision of the ADPF No. 54, issues related to decision-making autonomy were also considered, as well as the right to self-determination of the body, and personal privacy, arguments that can and are constantly sought in favor of the right to die in a dignified manner, at the moment determined by the terminal patient.

What the party advocated, and which was explained by the rapporteur himself, was, among other things, in broad analysis, the right of each woman to live their choices, values, and beliefs. Therefore, what is on the agenda is the woman's right to self-determination, acting under their autonomy and their right to privacy, seeking to safeguard their dignity, in deciding whether or not to continue the pregnancy.

On the subject, Jean L. Cohen (2012) has impressive writings, and in his article "Rethinking privacy: autonomy, identity, and the abortion controversy", he defends, among other things, the question of the necessary protection of the integrity of the dimensions of individual identities and the conceptions about the good that each person has, that is distinct from the conceptions of the collective identity.

Although Jean L. Cohen (2012) sought to reflect on abortion in the study referred to, its content fits perfectly with the case in question concerning issues inherent to the dignity of women.

According to her, the identity of the individual is not formed only by group values. In differentiated societies, privacy rights play important roles in protecting individuals' capacities for the formation, maintenance, and presentation to others of a coherent, authentic and distinct self-concept.

Thus, the new privacy rights highlighted in the aforementioned study also protect identity in the face of leveling in the name of a vague idea of community or the conception of the majority about the common good. They protect individual differences in the face of the "norm" adopted by the society or group to which the individual belongs. In short, not only the right to be left alone but the right to self-determination - decision-making autonomy - is protected by the right to privacy.

Thus, enjoying a right to privacy that guarantees decision-making autonomy means not being obliged to show the reasons for making ethical choices or even submitting to the group's reasons or judgments.

For Jean L. Cohen (2012), privacy rights, which grant decision-making autonomy over personal issues, ensure that individuals recognize the legality of their "ethical competence" concerning their self-definitions and decisions about what can be exposed and when.

Jean L. Cohen (2012) also addresses the question of what personal matters are covered by the right to privacy to which he alludes. He reports that he delves into issues related to procreation, including what he calls the right to abortion.

She emphasizes that all people are embodied individuals, that is, people are their bodies, the person's body is not extrinsic to what they are, so it is part of their dignity. Identities and individualities are intrinsically involved with bodies and what is made of them since the body is the person's way of being in the world. Thus, when it comes to the therapeutic anticipation of childbirth, what seems to be on the agenda is the identity and individuality of the woman, something intimate and deserving of protection.

In addition, self-determination over one's own body constitutes an exercise of freedom, enshrined in the constitutions since the advent of the Modern State in the 18th century, a freedom that is guaranteed by the Constitution of the Federative Republic of Brazil, in its article 5, item II (BRAZIL, 1988).

Thus, to impose on a woman to endure an unwanted pregnancy would be to impose on her an identity, the identity of a pregnant woman and a mother. The experience of pregnancy is a change in the personification of women and, consequently, in their identity and feeling of individuality that permeate the issue of bodily change.

Therefore, Jean L. Cohen (2012) points out that bodily integrity is essential for the identity of the individual and deserves to be protected as such by the privacy rights, and can only be disregarded by an even greater state interest, not least because it comes into the agenda, in this sense, the right of self-determination over the body itself, as seen.

So, he understands that the issues concerning procreation are fundamental since they involve the woman's identity, their processes of self-affirmation, and the understanding of themself. The question of the inviolability of the personality through the control of the body itself is essential to any notion of freedom.

In fact, the therapeutic anticipation of childbirth that has been discussed illustrates the struggle for women's autonomy.

On the subject, Tom L. Beauchamp and James F. Childress (2013) consider that, as distinct from political self-government, it is essential to personal self-government, the personal government of the "I" that is free, both on the part of other people's controlling interferences, and personal limitations that hinder the expressive choice of intention, such as inadequate understanding. The autonomous human being acts freely, according to a plan chosen by themself, just as an independent government manages its territory and defines its policies.

Thus, in strictly personal decisions, delicate by nature, it is important to prioritize the individual's decision-making autonomy and, as a consequence, specifically in the matters dealt here, their rights to self-determination of their own body and to personal privacy, which, at least it seems, cannot be different concerning the option for death with dignity, in which the terminal patient sometimes begs to be allowed to die autonomously and with dignity.

### 3.3 THE TORTURE ANALOGY

Another significant point considered in the Statement of Noncompliance with the Fundamental Precept No. 54, in which it was decided to "allow" the therapeutic anticipation of the delivery of an encephalic fetuses, was the question of the analogy to torture, in this case, concerning women, in continuing a pregnancy in which the extrauterine non-viability of the fetus is confirmed.

Even on the subject, Marco Aurélio Mello, in his vote, reported that the suffering of women forced to carry out pregnancy in such conditions could be so great that scholars of the subject correctly classify the state act that compels them as true torture.

Furthermore, he adds that by compelling the maintenance of pregnancy, one would be annihilating several of the most basic women's rights, imposing unreasonable suffering on them. The state ban on the therapeutic anticipation of childbirth, or the obligation to continue the pregnancy of an anencephalic fetus, which, in one way or another will remain in the death of the latter, therefore, goes against the basic principles of the constitutional system, such as, as listed by the minister, human dignity, freedom, self-determination, health, privacy, and recognition of sexual and reproductive rights. The minister reports that forcing the woman to keep the pregnancy, in this case, placing them in a kind of prison deprived of their own body,

depriving them of the minimum of freedom and self-determination, becomes something very similar to torture or to a sacrifice that cannot be asked for or demanded, from anyone and everyone.

What should one think, then, of the obligation to maintain invasive treatment embodied in true therapeutic obstinacy against the will of the terminal patient?

There is a recurring discussion about the need or unnecessary medical treatment that can be torturous to a terminally ill patient, and that certainly will not lead to a cure. Note that the Federal Constitution mentions the prohibition against torture and inhuman or degrading treatment.

So, to find out what the inhuman or degrading treatment is, checking how the constitutional order intended to regulate the matter, it is essential to, after, get into the medical field and the possible obstinacy of these professionals in the maintenance of human survival, causing real torture for the terminally ill.

In the regulation of the subject in question, the Brazilian Magna Carta states, in its article 5, item III, that no one will be subjected to torture or inhuman or degrading treatment. It is clear, therefore, that such a constitutional provision was made with the greater intention of protecting the integrity of the human person.

About what is inhuman or degrading, José Afonso da Silva (2010) deftly says that any form that may mitigate the person's dignity, either through physical suffering, of which torture is the highest form, or through moral suffering, matter inhuman or degrading. Furthermore, according to the author, the exact concept of what would be inhuman or degrading cannot be found even in international treaties so that, without a doubt, they are more felt than understood. One feels, therefore, when someone is treated

inhumanly or degrading because it constitutes, in this way, a value opposite to that of their dignity.

Certainly, the constitutional provision on-screen implies the prohibition of any act that seeks to undermine human dignity. Luiz Alberto David Araújo and Vidal Serrano Nunes Júnior (2010) argue that, generically, it can be said that torture and inhuman or degrading treatment reflect the same reality since the constituent legislator was concerned with the safety of physical and mental health of any person, thereby prohibiting the practice of torture, or inhuman or degrading treatment, under any pretext, which, consequently, would prohibit the transmission of medical treatment that would imply the mitigation of the patient's human dignity, causing them worthless and intense suffering.

Bearing in mind, in this way, that sometimes the medical treatment imposed on the terminal patient can cause them extremely great suffering, both concerning the physical aspect and the psychological aspect, then, would such treatment be inhuman or degrading, since from the point of view to be understood, without a doubt, the therapeutic measure would attack the dignity of the terminally ill.

On the subject, Debora Diniz (2007) describes a case in which she believes there is real torture due to the tenacity with which medical treatment is carried out. Without describing the patient's data, but with extreme propriety, the author reports that the case involved a baby of 8 (eight) months, with a degenerative, incurable clinical picture, and that required daily intervention sessions on the body, to maintain her survival. The child's parents reported those interventions as acts of torture since, hopelessly, they could not bring about a cure or change their clinical condition. The measures would only keep the baby alive, not acting to cure her or alleviate the symptoms of the disease. Those invasive measures, when alleviated the baby's suffering, were not seen by the parents as torturous but painful. According to them,

the thin line between torture and pain should be drawn by the result of each medical action: some improved the child's survival, and others served only as measures of therapeutic obstinacy.

In describing the above image, the author argues her position in the sense that torture is not in the infant's early death sentence, nor physical suffering, but in invasive medical procedures that are unable to offer any real alternative for reversing the clinical condition already established.

Wadi Lammêgo Bulos (2008) explains that in a society that aims to be fraternal and solidary, justice must be understood as an absolute value, and, equally since the dignity of the human person is one of the foundations that guide the Federative Republic of Brazil, there is no need to admit any treatment that proves to be malignant to man, including any forms of inhuman or degrading treatment, or torture.

Debora Diniz (2007), in this same sense, explains the right to death free from the torture of medicalization or the obstinacy of performing a useless treatment, characterized by its inhumanity, as a challenge for the society that associates death with failure. However, the dilemma encountered by the impotence of medicine in the face of upcoming death should not be faced in such a way as to compel the patient to submit a therapeutic obstinacy, which would characterize a true inhuman and degrading treatment, but visualized to help them at that crucial moment, through palliative treatments, that do not degenerate their human dignity and are not characterized as unconstitutional.

Under this bias, then, one cannot expose someone to inhuman or degrading treatment, just as one cannot force anyone to face therapy, and the choice should be considered on a case-by-case basis and respecting any decision not to undergo medical treatment that is characterized as unconstitutional, due to the affront to human dignity.

## 4 THE RIGHT TO DIE WITH DIGNITY AND THE POSSIBILITY THAT THE ARGUMENTS CONSIDERED IN THE DECISION OF THE NON-COMPLIANCE WITH FUNDAMENTAL PRECEPT NO. 54 MAY SERVE AS A GUIDE IN ITS IMPLEMENTATION

Like the right to live with dignity, the right to die with dignity is often claimed, not as a right opposite to that, but as something that is part of it, since death is an act of life. The last act of life.

Thus, it is not intended to conclude that the person has the right to suppress their own life since the concept of dignified death must be understood in the sense that death is the end of human existence, the final natural path to be followed by everyone, which is why, according to Luciano de Freitas Santoro (2010), dignity is a value to be respected at all times, there is a right to a dignified death as much as there is a right to a dignified life. There is no attempt to extinguish the right to live when, at the very end of life, one opts for the right to die in a peaceful and humanized way.

By the way, Letícia Ludwig Möller (2007) mentions that the inappropriate and excessive use of technologies applied to the medical treatment of terminally-stage patients, which end up prolonging a painful end of life, and often beyond what the patient wants, despising its right to exercise autonomy, confirms the need to affirm the existence of a right to die in a dignified manner.

According to the author, the terms "right to death" or "right to a dignified death" can be found in studies about the end of life that seek dialogue between different areas of knowledge, such as medicine, ethics, and the law. Those who defend the right to die with dignity, as a rule, see the situation of terminally ill patients, who are exposed to treatments that only delay the moment of their death, not causing benefits, but suffering and pain

- which does not mean that these authors wish to extend the defense to the practice of active euthanasia, frequently. Dying with dignity is usually related to the idea of dying in peace, preserving the patient's physical and spiritual integrity, or, similarly, dying at the right time, providing comfort and relief to the patient's suffering.

As Diaulas Costa Ribeiro (2006) emphasizes, dignified death is also a human right, understood as death without pain or anguish, in line with the will of the holder of the right to live and die. For the author, society's attitude is paradoxical often, emanating from a religiosity that religion overlooks, which includes the suffering of the spared animal, but which does not allow, with the same argument and under the same conditions, to remove the suffering of people capable and autonomous. As he reports, while the acceptance of euthanasia as an act of care is discussed without consensus, other movements are developed and build solutions based on principles also invoked in euthanasia: autonomy and dignity at the end of life.

So, if the arguments presented are used in favor of the woman's right to choose to continue with the pregnancy of an anencephalic fetus, or not, why not in a different case, but equivalent, as is the case with the right to die dignified, autonomous, free from all sorts of suffering and psychophysical degradation?

It was decided that the anencephalic fetus cannot properly be considered a life due to the absence of extrauterine life expectancy. It is not intended, therefore, to make a clash between the cases but to consider the arguments that may be common to them. Even because if the anencephalic fetus has no extrauterine life expectancy, the terminal patient already has death as something urgent. What happens is that, sometimes, this person prefers to die at the time and in the way determined by them, to preserve themself from extreme suffering, seeking shelter for their dignity.

At first, in this article, the issue of the Secular State was related as a foundational argument in the decision of the ADPF No. 54. It is questioned the possibility that the same reasoning can help in the fight in favor of the right to die with dignity.

It should be noted that if the State is absolutely neutral, it cannot, or should not, allow itself to be influenced by religious arguments. Obviously, we are not preaching that religiosity is unimportant or that religious arguments should not be listened to. We live in a Democratic Law State, in which everyone can express their opinion. What cannot happen is to make such positions serve as a guide in important decisions by the State, as was the case with anencephalic fetuses, and as is the matter of dignified death, in which the sacredness of human life is often invoked as a clash element.

Ronald Dworkin (2003) reports that the conviction that human life is sacred offers a strong emotional basis for opposition to a dignified death, but, as well-characterized by the rapporteur of the Allegation of Non-compliance with Fundamental Precept No. 54, Minister Marco Aurélio Mello, being Brazil, a secular republic, appears in an absolutely neutral way concerning religions.

The sacred character attributed to human life and its analysis as God's property, granted by him to mankind, thus, cannot in any way influence the state's position in the eventual discussion of a dignified death.

Thus, another element present in the discussion of the ADPF in vogue, which corroborated for the debate, refers to the protection of decision-making autonomy, the self-determination of the body, and the personal privacy of women, in discerning themselves about pregnancy maintenance or therapeutic anticipation of childbirth.

Likewise, about dignified death, the search for protection of the patient's decision-making autonomy, and, consequently, of their rights to self-determination of their own body and privacy, is an argument constantly

invoked and has relevance, since the respect to autonomy expresses the respect for the subject's dignity.

Regarding decision-making autonomy and the right to die with dignity, Diaulas Costa Ribeiro (2006) asserts that living life with autonomy is a potestative right, which can be exercised without the consent of third parties. No one needs someone else licenses to live their own life, especially in countries without the death penalty. Once this exception has been made, no one, nor the State, can impose restrictions on this right, which is why it is called supreme. That does not limit a rereading of the right to live, as it is a potestative right, which is renounced only by its holder. If it were not renounceable, it would not be a right but a "duty" to live. And as a "duty" to live, it would generate legal consequences different from those known today, starting with the punishment of suicide attempts, prohibition of extreme sports, and even risky activities, and would trigger the mechanization of life beyond life, causing inhuman and degrading treatments to the ill.

Thus, when preserving the terminal patient's autonomy, one must also keep in mind the preservation of their rights to privacy and to their own body, rights that weigh heavily in the patient's decision to die peacefully and humanely. To comply with their autonomous decision is to safeguard several of their most elementary rights and, as an ultimate goal, protect their personal dignity.

Finally, but not least, the third argument analyzed here, and considered in ADPF No. 54, refers to the prohibition of torture and inhuman or degrading treatment. In the action in question, it was argued that it is an analogy to torture to make a woman proceed with a pregnancy of an anencephalic fetus contrary to her will.

Could forcing the continuation of invasive and useless treatment in terms of cure or alleviation of suffering be considered genuine inhuman/ degrading treatment, or even torture? Could then such conduct be used as an argument in the face of the duty to maintain human survival and in favor of defending the right to die with dignity?

According to what could be examined before, there are, in fact, treatments that cause greater suffering than the disease that affects the ill and that do not bring a cure or even relief to their suffering. In this way, the subject's dignity is undermined, and, in fact, the Federal Constitution expressly prohibits any type of torture or inhuman or degrading treatment.

On the prohibition of the imposition of degrading medical treatment, Fernando Aith (2007) explains that the constitutional provision dedicated to the prohibition of torture and inhuman or degrading treatment covers medical treatments, as well as other actions related to medical practice. From that, the physical and mental integrity of the human being is legally protected against possible medical treatments - for example, banning of shocks for the treatment of the mentally ill -, against the carrying out of scientific research in human guinea pigs, against the commercialization of human organs, among other procedures that can be characterized as torture or inhuman or degrading treatment, which, therefore, would include the useless treatment inflicted on the terminal patient.

Thus, medical interventions that cause more harm and suffering than the illness that affects the sick person and that are characterized as pure therapeutic obstinacy must be refuted if they cannot bring a cure or, at the very least, an improvement in the patient's clinical condition.

Finally, one can see the relevance of the position according to which there is the possibility of carrying out a dignified death. Likewise, the issues raised concerning the secularity of the State, the protection of decision-making autonomy, the right to one's own body and the right to privacy, and, finally, the prohibition of torture and inhuman or degrading treatment, are extremely important and deserve shelter in the national legal system,

including decisions of personal nature, such as the decision for the best time and the best way to die, even if one does not agree with such a decision.

### **5 CONCLUSION**

The subject discussed in the current study is extremely controversial, and its analysis becomes imperative. The fight for the right to die with dignity has taken on increasingly significant proportions and arguments in favor of the prerogative that the terminal patient can choose the best time and the best way to die are many.

We sought, here, to study some of the arguments listed in the decision of the Complaint of Non-Compliance with the Fundamental Precept No. 54 and to verify whether, in line with the Brazilian legal system, they can also serve as a foundation in the search for the right to die in a dignified manner.

Obviously, the issues are distinct, but it cannot be denied that, despite this, they are connected and are usually understood together, precisely because of the search, as the ultimate goal, to preserve personal dignity, through the protection of decision-making autonomy, or the pregnant woman, or the terminal patient.

Thus, what was noticed was that the ideals analyzed in the study, weighted in ADPF No. 54 as arguments in favor of the declaration of the unconstitutionality of the interpretation according to which the termination of pregnancy with an anencephalic fetus would be conduct typified by the normative set of articles 124, 126 and 128, items I and II, of the Penal Code, are very significant, and denote rights that need to be preserved.

And speaking of those ideals, it should be noted that the first of them, relating to the secularity of the State, was raised with controversy in the analyzed decision, and has its importance since we live in a neutral state, and,

given this neutrality, the strictly religious arguments influence decisions, as verified in ADPF No. 54, and as it should happen concerning dignified death, therefore. The sacredness of life, imbued with religiosity, cannot and should not, under this argument, be used as an obstacle to decisions by the State.

The second point analyzed corresponds to the rights to decision-making autonomy, self-determination of one's own body, and privacy. There is no doubt about the importance of such rights, so much so that they were seen as a paradigm for deciding in favor of the possibility of therapeutic anticipation of childbirth in the case of fetuses with anencephaly. It was intended, therefore, to safeguard the woman's right to choose to continue the pregnancy, or not, based precisely on the decision-making autonomy. Likewise, the possibility of living a dignified death, as the last act of life to be lived, in an autonomous and dignified way, preserving the privacy of the terminal patient and their right to their own body, respecting their decision, is a prerogative constantly sought and, yes, it deserves to be reflected and weighed to the detriment of the protection of human survival without any quality.

In this north, the third point concerns the constitutional prohibition of torture and inhuman or degrading treatment. It turned out to be a case of real torture forcing a woman to carry an anencephalic fetus, that is, to maintain the pregnancy against her will. Likewise, forcing a terminally ill patient to face an extremely invasive treatment, with no possibility of cure or improvement in their clinical condition, according to everything exposed in the study, seems to be a genuine inhumane treatment, in addition to the torture consubstantiated in therapeutic obstinacy.

Therefore, what can be seen is that one may not even agree with the therapeutic anticipation of childbirth in the case of fetuses with anencephaly, nor with the idea of the possibility of opting for the best time and the best way to die, with dignity. However, it cannot be ignored that the elements presented in this study are very strong, so much so that they were used as

a foundation for the explained decision and, similarly, are strongly indicated as a guide in decisions taken at the end of the life, when the right to die with dignity is defended. Hence, it is considered that they should indeed be reflected, also in the analysis of the search for death with dignity.

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# THE DECISION-MAKING AUTONOMY IN THE CONCRETE PLAN: CASE STUDY INVOLVING THE SEARCH FOR THE RIGHT TO A DIGNIFIED DEATH AROUND THE WORLD

### **ABSTRACT**

This work aims to investigate cases of the search for the right to a dignified death in the most diverse contexts - countries and ways of realization. Therefore, as a research problem, it has the questioning about the reality of the cases involving decision-making autonomy specifically concerning the law. For the objective to be fulfilled, an exploratory-explanatory, qualitative bibliographic research will be carried out, using the deductive approach method. As a result of the research in question, in summary, it can be said that cases of a search for some form of dignified death - assisted suicide, euthanasia, or even orthothanasia - are very frequent in all the countries surveyed, which denotes how real the problem is, even though similar cases are not known in Brazil. In conclusion, there is an urgent need to enforce this right, nationally or internationally - which, it should be noted, has already been occurring in the latter case.

**Keywords:** decision-making autonomy; dignified death; cases.

### 1 INTRODUCTION

Would dignified death be a purely academic matter on the margins of the everyday reality of courts around the world, or does the theme appear from time to time before courts in the most diverse countries? Here is a question that is not too difficult to answer if one ponders stories that took place in different spaces and times: the fight occurs every day! Thus, it is essential to analyze some cases that involve the search for the right to death with dignity. The theme is real and palpable and so much so that around the world, there are countless cases of people who, armed with their decision-making autonomy, fight for the right to die as they consider dignified. In the same way, sometimes the family seeks such right, based primarily on what they know to be the desire of individuals who can no longer express it.

In the following lines, we will seek to study some cases with worldwide repercussions for the right to die with dignity. Some of them date back years, and some are very recent, which expresses, without a doubt, that, although much has already been discussed, much remains to be debated about it. It is true that, in terms of Brazil, there are no reports that have had repercussions of cases of search, in court, for the right to death with personal dignity provided by euthanasia or assisted suicide. That makes us believe that there is no such desire/need in people's minds. The cases that follow, although all occurred in other countries, illustrate how concrete and present is the debate here proposed.

The discussion will be brought up by proposing the analysis of cases known worldwide. To that result, a bibliographic search was carried out from reliable sources, and the deductive method was applied.

### 2 CASES INVOLVING THE SEARCH FOR THE RIGHT TO A DIGNIFIED DEATH

Death with personal dignity can occur in some ways, including euthanasia, assisted suicide, and orthothanasia. As detailed elsewhere, the essay aims to explain some cases of the search for the realization of a dignified death, in some of the ways explained. To ponder the cases that

have already occurred (and that have been occurring) is one of the ways of really knowing and in-depth the problem, which, despite insistently being selfless, needs to be discussed and known legally and socially. Eight cases of the struggle for the right to a dignified death that has occurred around the world will be listed and considered from now on, starting with the case of Brittany Maynard.

### 2.1 BRITTANY MAYNARD

The case of Brittany Maynard faithfully expresses the search for the right to die with dignity based on the decision-making autonomy of a patient in an advanced stage of a terminal illness. Brittany was diagnosed, in 2014, with aggressive, incurable, and terminal cancer in the brain and decided to anticipate death instead of waiting for it to arrive after much pain and suffering.

On the official page of the foundation created by her to support the right to die with dignity, The Brittany Maynard Fund (2016), it appears that, at first, she underwent treatment through surgery, but cancer continued to progress. The doctors then gave her only a few months to live, full of pain and suffering and in which the palliative treatment would make her suffer and feel countless pains, in addition to those arising from her illness.

Brittany, then, armed with her decision-making autonomy, and determined to avoid the agonizing death that cancer would bring her, moved from California to the state of Oregon, to be able to die with dignity, as she would like, since, in this last state, assisted suicide was allowed, and at that time, there was no such possibility in California.

Brittany's final weeks were dedicated to fighting for people's right to self-determination concerning their death. She intended that other people could have access to a peaceful and humanized end of life, in any place or state.

On November 1, 2014, then, Brittany passed away the way she thought was best for her, surrounded by her family and friends. On October 5, 2015, California Governor Jerry Brown signed into law the law that legalizes medical-assisted suicide, which set a milestone, perhaps tied to Brittany's struggle. The law went into effect in June 2016.

### 2.2 CHANTAL SÉBIRE

Another case that has taken on worldwide proportions is the case of the French Chantal Sébire. Chantal was stricken with a very rare type of cancer in the nasal cavity (esthesioneuroblastoma) that, progressively, would damage her brain, possibly leading to death. It is reported that Chantal already suffered from difficulties in seeing, feeling tastes, and smells, that is, the senses of sight, taste, and smell were already impaired as a result of the disease. Besides, Chantal's appearance was truly frightening, and the pain was terrible, as seen in Crawley (2008).

In France, the Leonetti Law (Law no. 2005-370), approved in 2005, does not provide for cases like Chantal's, that is, despite the suspension of artificial life support treatments, which are useless or disproportionate, active conduct that causes death, as would happen in the case of Chantal, is not allowed (FRANCE, 2005).

According to BBC Brasil (2008), Chantal appealed to the then French President Nicolas Sarkozy, begging that she would be given the right to die with dignity. Afterward, she sought the same right before the court of Dijon, where she resided, without success, however. With all her requests denied, in March 2008, Chantal committed suicide, a fact that provoked intense discussions in her country involving the topic related to assisted death, euthanasia, and related concepts.

### 2.3 DIANE PRETTY

British Diane Pretty led an intense legal battle in the fight for the right to die as she considered to be dignity. Diane was affected by motor neuron disease, a progressive neurodegenerative disease of the motor cells within the central nervous system. Gradually her muscles were being destroyed by the disease, which made Diane getting increasingly hard to communicate, in need of a wheelchair, and fed through a tube, according to the website of the British organization *Dignity in Dying* (2016). Suffocation is probably the cause of death in those circumstances, as there is the deficiency of the respiratory muscles combined with the weakness of the muscles that control speech and swallowing.

Given her clinical condition, in which life expectancy was only a few months, the patient requested permission to perform an assisted suicide. Who would provide the necessary assistance, in this case, would be Diane's husband, according to what is obtained on the website of the newspaper *El País* (2002).

The request was rejected before the appropriate judicial bodies, and, having exhausted the possibilities in all instances, it then arrived in Strasbourg, where it was submitted to the European Court of Human Rights. From the judicial dispute Diane Pretty *versus* the United Kingdom, there is, thus, the Application (appeal) n. 2.346/2002, at the Court in question (STRASBOURG, 2002). The request was rejected, confirming the impossibility of carrying out the assisted suicide, according to the decision in vogue.

According to BBC Brasil (2002), Diane's family announced, after her death, which occurred in May 2002. Her death happened, as it is shown, precisely in the way she would not like it to happen, through intense suffering generated by breathing difficulties, a consequence of her illness.

### 2.4 MARCELO DIEZ

Another case that, recently, was a paradigm of discussion, is the case of the Argentine Marcelo Diez. Marcelo, after suffering an automobile accident remained in a vegetative state, a situation that lasted for twenty years. After an emblematic decision of the Supreme Court of Justice of the Nation, the patient won, in July 2015, the right to die in a dignified manner (ARGENTINA, 2015).

Although when analyzing the case superficially, it does not seem, at first, to be directly a case of the struggle for respect for decision-making autonomy and the right to bodily self-determination, given Marcelo's vegetative state, it is, and it is undeniable the importance that it assumed, in global terms, being, undoubtedly, a case of search for the right to death with dignity. That is because, according to the information provided by family members, Marcelo expressed the desire, when lucid, that his life should not be artificially prolonged, in the event of the occurrence of a situation similar to this, although he left nothing in writing, because, at the time he suffered the accident, no legislation in Argentina foresaw such a possibility.

Faced with the desire expressed by Marcelo while lucid, his sisters asked in court to suspend the measures that kept the patient artificially alive for decades. According to the Centro de Información Judicial - CIJ (2015), the Supreme Court upheld the decision of the Superior Court of Justice of the province of Neuquén, considering the request to be well-founded, but, previously, for the certainty of the irreversible character of the state of Marcelo, ordered medical studies to be carried out to complement those that had already been done. The studies confirmed the irreversible and incurable character and did not point out scientific elements that would allow believing in the possibilities of recovering the patient's condition.

Thus, in this case, the Supreme Court considered that the Patient Rights Law (*Ley de Derechos del Paciente* – 26.529), modified in 2012 by the Law 26.742 (*Ley sobre derechos del paciente*, *historia clinica y consentimiento informado*) (ARGENTINA, 2012), contemplates situations like Marcelo's, in which individuals cannot express their consent, and authorizes family members to testify on their will regarding the treatments they want or not to be given. They also decided that Marcelo's self-determination should be guaranteed. The Court declared that it was not a case of euthanasia and emphasized the importance of exclusively respecting the patient's will regarding end-of-life decisions.

### 2.5 NANCY CRUZAN

The episode involving the American Nancy Cruzan is another that took on significant proportions in global terms. Nancy suffered an automobile accident on January 11, 1983, at the age of 25, in the interior of the state of Missouri, where she resided. Due to the lack of oxygenation in the brain, Nancy remained with permanent brain damage and, in the same way, in what can be called a permanent vegetative state.

According to Goldim (2005a), the patient was fed through a tube. Over the years, all attempts of rehabilitation have been unsuccessful, so Nancy's family chose to request that the nutrition and hydration procedures to be stopped. It is reported that the medical team, as well as the institution responsible for Nancy's case, refused to carry out such a procedure without judicial authorization.

The family then appealed to the court to grant the daughter the right to die through the removal of the nutrition and hydration supports. After a long legal battle, the family's demand was finally met. As it appears, on December 15, 1990, Nancy's feeding tube was removed, and she died on the 26th of that same month. The following epitaph can be found on Nancy's grave: "Born July 20, 1957. Departed January 11, 1983. At peace December 26, 1990".

### 2.6 RAMÓN SAMPEDRO

The case of Ramón Sampedro Cameán represents a significant case of a struggle for the right to die in dignity, which culminated, unfortunately, in the death of the plaintiff without the "permission" of the State. It is, therefore, a case of assisted suicide carried out by Ramón Sampedro, with the help of interposed persons who acted out for merciful motives, in the face of his conviction in the desire to die in a dignified manner.

Ramón Sampedro Cameán, quadriplegic since August 23, 1968, when, while diving in the sea, hit his head, asked the Spanish justice to be granted the right to die with dignity through euthanasia. In summary, despite tireless attempts, in none of the instances did the plaintiff succeed in his request, as extracted from the website of the Spanish association *Asociación Federal Derecho a Morir Dignamente - AFDMD* (2016).

Thus, after almost three decades of fighting for the right to die in dignity, on January 12, 1998, Ramón Sampedro Cameán died as a result of ingesting potassium cyanide. The case is a truly assisted suicide. According to Goldim (2007), Ramón's suicide was recorded, and in the video, it remains clear that the desire to have an early death came from him, and although acts were performed by third parties to facilitate the action, he was the one who, with the help of a straw, ingested all the substance contained in a glass near his face, which led to his death in a few moments.

It is known that Ramona Maneiro, a friend of Ramón, helped him in the practice of the suicide, even though he mentioned, in the recorded video, that there was a plurality of solidary contacts, which made the potassium cyanide reach him, and there is the information that each of these friends performed a small act that helped Ramón to succeed in his attempt, acts that, by themselves, do not constitute a crime. Ramona was investigated and, at first, arrested on charges of cooperation necessary for suicide, but, due to insufficient evidence, soon after she was released, according to the information exposed by the *Asociación Federal Derecho a Morir Dignamente - AFDMD* (2016). Ramona confessed, seven years later, to have helped with the suicide. Even so, once the prescription of the crime occurred, there was an extinction of its punishment.

The case of Ramón Sampedro Cameán, without a doubt, is a paradigmatic case of fighting for the right to die with dignity. Although he did not suffer from a terminal illness, Ramón did not consider it dignity to live the way he did, with a "living head" in a "dead body" and, in his conception, formed at the height of his lucidity and matured during nothing less than three decades death was the best solution.

Around the world, the case has sparked, and even today sparks, debates about dignified death and the possibility of euthanasia and / or assisted suicide.

### 2.7 TERRI SCHIAVO

The American from the state of Florida, Theresa Marie Schindler-Schiavo, or simply Terri Schiavo, suffered a cardiac arrest in 1990, allegedly related to the loss of potassium resulting from serious bulimia (eating disorder associated with binge eating diet followed by extreme behaviors aimed at weight loss, such as the use of laxatives, and especially, the act of causing vomiting). According to Goldim (2005b), Terri remained for at least

five minutes without blood flow in the brain, and, due to brain damage, she went into a vegetative state.

After much family discussion, especially between Terri's husband, Michael Schiavo, who was in favor of removing the devices that kept the patient nourished and hydrated, and her parents (Mary and Bob Schindler) and her brothers, who were opposed to the practice, in addition to intense legal and even political dispute, and after generating reflections around the world, according to Vieira (2009), the supports were suspended, and Terri died on March 31, 2005.

In the course of the dispute, according to Goldim (2005b), three times Terri's husband won in court the right to remove the tube that kept her nourished and hydrated. The first two times, the authorization was reversed, and, on March 19, 2005, the probe was removed for the third time, remaining so until the patient's death on the 31st. The case in question took on gigantic proportions and had great complexity, which can be investigated on the family members' litigation, among themselves, and concerning society, doctors, the justice system, the United States House of Representatives, and the Florida Government (remembering that in the state of Florida no legislation allows assisted/anticipated death in any way).

Furthermore, the controversy revolved around Terri's decision-making autonomy. Her husband claimed that the patient, when lucid, verbally expressed that, in cases like this, she would not like to be kept on survival. The *Living Will* is admitted under American law, and if Terri had documented her last will in writing, the case would probably not take on such a large proportion. What happens is that there was disagreement about Terri's last will, and her parents claimed that their daughter had never expressed the wish that, in the event of a similar situation to the one she was in, she would prefer to have died through disconnection of devices, and/or removal of the vital support, or the probe, as occurred.

According to Vieira (2009), the American courts have already authorized the suspension of treatments that kept the patient on survival based on testimonial evidence that this was their will when able and conscious, which reinforces that the mismatch of the husband's opinion and the family was one of the reasons why the decision in the situation became very difficult.

### 2.8 VINCENT LAMBERT

Another emblematic episode is the case of the Frenchman Vincent Lambert. The European Court of Human Rights, in Strasbourg, in 2015, confirmed the decision of the French justice and allowed the disconnection of the devices that kept him alive.

Lambert suffered an automobile accident in 2008, according to BBC Brasil (2015), when he became quadriplegic and in a chronic vegetative state. Thus, the patient's wife sought in court to grant Lambert the right to die with dignity by turning off the devices that ensured his survival.

As has been established, in France, since 2005, with the advent of the Leonetti Law (Law No. 2005-370), there is the possibility of suspending useless, unnecessary, or disproportionate treatments that lead to the artificial maintenance of life. The European Court of Human Rights, in this case, made clear the existence of the French law for cases like the one in question.

The case has generated controversy even in the patient's own family. His wife and some of his siblings were supportive, and his parents and other siblings were opposed to the suspension of the life support. For this reason, the agenda reached Strasbourg, where, finally, after a considerable legal dispute, there was a ruling in favor of the suspension.

Despite the Court's decision, Vincent still survived for a long time. Vincent Lambert's case, as well as Chantal Sébire's, is the trigger for debates

on the topic of dignified death in France, and recently, in 2015, legislation was introduced in the country allowing the continuous sedation of patients in end of life and who are in deep suffering, when their condition is susceptible to lead to rapid death. Finally, in July 2019, after attending a court decision, doctors began to withdraw the treatment that kept him alive, which culminated in his death, after more than a decade in a vegetative state (G1, 2019), which generated several controversies still faced today even after his death (*EL PAÍS*, 2019).

Vincent profoundly marked the worldwide debate about dignified death, just as it did within his own family. It is his case, therefore, a symbol of what many others are fighting.

### 3 CONCLUSION

The objective of the study in question was to show the world's reality in terms of requests to respect the right to death with dignity, in a broad way, dealing with assisted suicide, and/or euthanasia, and orthothanasia, so that it was found, as mentioned throughout this essay, that this right is daily contested, demonstrating the urgency of the analysis, whether in the world or national terms, of the possibility that it will be carried out, either through the formalization of legislation (which has already been happening) or through decisions that put the existing law into practice (which has also occurred on several occasions, as seen elsewhere).

Thus, some symbolic cases of the struggle for the right to death with dignity were listed. All of them in which unrestricted respect for decision-making autonomy was sought, whether expressed by the patient who requested the death with dignity, whether manifested through family members, who expressed what they acknowledged to be the patient's will, now unconscious.

So, the first case listed was that of Brittany Maynard, who, diagnosed with terminal cancer, fought tirelessly for the right to die with dignity and eventually moved from California, where until then assisted suicide was not allowed, to Oregon, a place where she fulfilled her desire to live her last moments of life, as well as her death, with dignity and surrounded by the people she considered most. Nowadays, in California, assisted suicide is allowed, and if so it is, much was because the discussions got heated with Brittany's case.

The second case presented was that of the French Chantal Sébire, who, after unsuccessful attempts to realize the right to die with dignity by legal means, ended up committing suicide. Diane Pretty was the protagonist of the third case presented. After her fight, the British unfortunately ended up dying from the disease that affected her. In the fourth case, the Argentine Marcelo Diez's family's battle was described to carry out what they knew was his will: to die with dignity if he ever found himself in the situation he was. The fifth case referred to Nancy Cruzan and is another in which the family sought to materialize and did so what they knew was the will of the patient, a citizen of the state of Missouri: death if she were to remain in a situation of permanent vegetative state.

The sixth case is perhaps the best known worldwide: the case of Spaniard Ramón Sampedro. After decades of a quadriplegic and several years of struggle in the Spanish justice system to allow him to die in the way he considered worthy, Ramón ended up carrying out an assisted suicide clandestinely.

Terri Schiavo is the seventh case presented. The husband of the American citizen of the state of Florida, Michael Schiavo, sought to be granted to the wife in a vegetative state the prerogative of death with dignity, and, after much controversy, including with Terri's family members, consolidated the intention, that he claimed to be the patient's will.

The eighth and final case is that of the French Vincent Lambert. Also, through family controversies, Vincent's wife sought in court the right to suspend the vital foundations that artificially kept him in survival. The case came to the European Court of Human Rights, which ruled the demand favorable, although, for a long time, there was no news of the shutdown of Vincent Lambert's life support devices, which occurred only in 2019.

Finally, on the one hand, with the finding, in the cases presented, that the search for death with dignity is present in courts around the world, and not something merely theoretical. On the other hand, it shows how much we still have to evolve in the subject in question, and in all of those in which one fights for, in truth, is respect for decision-making autonomy, personal identity, and the search for the construction of one's personality. The watchword in these cases is still "fight".

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