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Dignified death as a right: the legal visibility of finitude

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Abstract

The right to a dignified death is largely overlooked by Brazilian law. This neglect of the end-of-life process and its ramifications is the focus of this study, which aims at an exploratory survey to identify pertinent aspects requiring development to ensure a dignified end-of-life experience. In total, 50 publications were examined with online and physical surveys of works published up to March 2023. They express concerns regarding ethical dilemmas in caring for individuals nearing the end of life, yet they do not delve into existing mechanisms for safeguarding end-of-life dignity or identify areas that still lack standardization to ensure effective care. This study should contribute to the enhancement of critical perspectives on the issue of end-of-life experiences, considering current safeguards, the legal boundaries set by the State, and potential future strides toward advancing studies aimed at the practical update of the Brazilian legal system.

Keywords: Human rights. Civil rights. Value of life. Right to die. Hospice care.

Resumo

Morte digna como direito: visibilidade jurídica da finitude

O direito à morte digna é majoritariamente ignorado pelo ordenamento brasileiro. Essa invisibilidade do processo de finitude e suas consequências são tema deste estudo, que objetiva realizar um levantamento exploratório para identificar pontos relevantes que devem ser desenvolvidos para garantir um processo de finitude digno. Foram analisadas 50 publicações, mediante levantamento *online* e físico de obras publicadas até março de 2023. Os estudos analisados expressam preocupação com dilemas éticos do cuidar do ser humano em finitude, mas não analisam formas existentes de tutela da finitude nem quais searas ainda são carentes de normatização para dar eficácia a esse cuidado. Espera-se que esta pesquisa contribua para fortalecer o olhar crítico ao tema, considerando as atuais tutelas da finitude, os limites legais do Estado e os potenciais passos futuros para fazer avançar os estudos aplicados à atualização prática do ordenamento brasileiro.

Palavras-chave: Direitos humanos. Direitos civis. Valor da vida. Direito a morrer. Cuidados paliativos na terminalidade da vida.

Resumen

La muerte digna como derecho: visibilidad jurídica de la finitud

El derecho a una muerte digna es ampliamente ignorado por el ordenamiento jurídico brasileño. Esta invisibilidad del proceso de finitud y sus consecuencias son el objeto de este estudio, que tiene como objetivo realizar una encuesta exploratoria para identificar los puntos relevantes que deben desarrollarse para garantizar un proceso de finitud digno. Se analizaron 50 publicaciones a través de una encuesta online y física de obras publicadas hasta marzo de 2023. Los estudios analizados expresan preocupación por los dilemas éticos de la atención a seres humanos en finitud, pero no analizan las formas de protección a la finitud existentes ni cuáles son las áreas que aún necesitan regulación para hacer efectiva esta atención. Se espera que esta investigación contribuya a fortalecer la visión crítica de la finitud, considerando la protección actual de la finitud, los límites jurídicos del Estado y los posibles pasos futuros para avanzar en los estudios aplicados a la actualización práctica del sistema jurídico brasileño.

Palabras clave: Derechos humanos. Derechos civiles. Valor de la vida. Derecho a morir. Cuidados paliativos al final de la vida.

The authors declare no conflict of interest.

Update

Birth, life, and death are inevitable realities and, thus, are subjects of discussion across all branches of the human sciences. Particularly regarding death, society tends to shy away from contemplating human finitude, let alone engaging in discussions or ensuring dignity in the end-of-life process. However, despite being deemed taboo, death—understood synonymously with the Greek term *thánatos* [1]—should be deliberated upon as fervently as life, especially considering the marginalization of individuals undergoing the dying process in Brazil.

Acknowledging those who are rendered invisible daily, this study aims to illustrate that the process of death, alongside mourning, constitutes essential experiences for the assurance and fulfillment of the right to life and dignity since death is basically life's final experience.

The advancement of medicine and the aging of the Brazilian population [2] raise the likelihood of situations involving acquired disabilities [3] and individuals afflicted with incurable ailments, which leads to a surge in the people necessitating palliative care. According to the National Academy of Palliative Care, an estimated 20 million individuals globally require palliative care, with projections that this figure could double to 40 million if the initial stages of diagnosis are considered [4].

In the realm of law, numerous publications in bioethics delve into potential practices concerning the last moments of life or the management of death. Many of these publications focus on comparative law or explore the practices of orthothanasia, dysthanasia, and euthanasia.

However, few laws and scattered regulations exist concerning the legal regulation of the finiteness of life, which are primarily affiliated with the Federal Council of Medicine (CFM) and wield limited influence over the broader legal system. Moreover, there is a notable absence of legal frameworks governing the process of death and a deficiency in understanding the concept and imperative to adhere to constitutional principles during life's ending stages.

The discourse surrounding palliative care and the human finiteness process is broad, inviting various avenues of debate, such as funding considerations in certain addressed situations or protection within the realms of criminal and civil policy. While these approaches warrant thorough examination, we do not aim to exhaustively cover these points herein.

Definition of the right to life and death

In legal terms, life and death are regarded as institutions, each with presumed meanings, as there is no definitive kabbalistic definition for either. The concept of life is enshrined in Article 5, Section I, of the Federal Constitution, which states:

Article 5 – All persons are equal before the law, without distinction of any kind, guaranteeing Brazilians and foreigners residing in the country the inviolability of the right to life (...) [5].

And it is also delineated in the 2002 Civil Code, under Article 2:

Article 2 – The civil personality of a person begins at birth; however, the law protects the rights of the unborn child from conception [6].

The right to life is extensively referenced and safeguarded through international treaties and agreements, such as the International Covenant on Civil and Political Rights (1966), Article 6, §1; the Pact of San José of Costa Rica, Article 4 (1969); and the Universal Declaration of Human Rights (1948), Article 3.

The right to life is inherent to the human person. This right must be protected by law. No one may be arbitrarily deprived of their life [7].

Every person has the right to have their life respected. This right must be safeguarded by law and, in general, recognized from the moment of conception; no individual can be arbitrarily deprived of life [8].

Every person is granted the right to life, freedom, and personal security [9].

Although legally defining the term "life" is a difficult task, it is feasible to acknowledge that the law regards it as an inviolable right inherent to the human person.

It is pertinent to consider the perspectives developed by legal doctrine regarding the word "life." Pontes de Miranda observes that *the right to life is innate; anyone born alive inherently holds this right* (...). *Consent from a person subjected to acts against their life, such as homicide or attempted murder, does not absolve the contravention of the right, which is why the right to life is inalienable.* (...) *The right to life is ubiquitous, existing within any branch of law, including the supra-state legal system. Hence, it is unreasonable to confine it solely to private law* [10].

Alfredo Orgaz, as cited by Luciana Mendes Pereira Roberto, elucidates that *life serves as an essential prerequisite for personhood's quality rather than a subjective right, being publicly safeguarded irrespective of individuals' desires. Consequently, individual consent holds no sway in altering this protection, rendering a genuine private "right" to life unattainable. Thus, all legal actions wherein an individual places their life at another's disposal or subjects themselves to grave peril are entirely canceled* [11].

Jakobs [12], in a distinct perspective, asserts that the primary value is not merely life as a biological phenomenon but rather its quality or, at the very least, its sustainability, given that living does not equate to perpetual health concerns. Likewise, Calsamiglia's definition, as presented by Dias, posits that *life's value lies not solely in our existence as living beings but rather in the conduct and achievements realized within it* [13].

Within the constitutional scope, Moraes underscores that the right to life *stands as the most fundamental of all, constituting a prerequisite for the existence and exercise of all others* [14]. Furthermore, Branco explains that *it would not make sense to declare any other (right) if, first, the right to be alive to enjoy it was not safeguarded. The inherent abstract weight of the right to life, stemming from its paramount significance, supersedes any other interest* [15].

Moreover, Pontes de Miranda delved into the dual nature of death concerning the right to life, positing that *the right to life inherently implies the right to death. If a person is given the right to live, they are also granted the right to die.* (...) *Every right corresponds to duty, but someone else's duty*; (...) *there is no taking away the right to live and the right to die. Thus, if such a right existed, aiding suicide would remain unpunished* [16].

The treatment of death within the Brazilian legal system is comparatively recent and less developed than that of life, and like the concept life, that of death is not clearly defined. The Civil Code discusses, in art. 6, that the *existence of a natural person ends with death*, but does not define what death would be [6]; and the Penal Code, art. 121, refers to killing someone: *Penalty – imprisonment from six to twenty years* [17]. The objective of such regulations, in this context, is to uphold the right to life, as protected by the Federal Constitution.

Additionally, the definition of death is outlined in Law 9,434/1997, which governs organ donation:

Article 3 – The post-mortem removal of tissues, organs, or body parts intended for transplantation or treatment requires a prior diagnosis of brain death, confirmed, and documented by two physicians (...), *utilizing clinical and technological criteria defined by the resolution of the Federal Council of Medicine* [13].

Another noteworthy perspective on the definition of death is presented by Gardiner and collaborators, who assert *a growing consensus within the medical community, that is, that all human death is anatomically located in the brain. Consequently, human death involves an irreversible loss of consciousness, coupled with the irreversible loss of the capacity to breathe* [19]. Hence, both legally and medically, brain death is acknowledged as the moment in which life ceases [20].

Finally, it is essential to consider the philological definitions of the terms:

Death: noun. end of life, death, termination, destruction [21].

Life: [from Lat. vita] noun (...) *2. State or condition of organisms that remain active from birth to death; existence.* (...) *5. The period elapsed from birth to death; existence* [22].

Considering such definitions, it is noteworthy that death is not merely portrayed as the antithesis of life, but rather as the concluding episode marking its termination—the final act of life. It is understood that the full exercise of the right to life

hinges upon the assurance of a dignified death, underscored by the principle of human dignity.

This article adopts a comprehensive view, in alignment with Alfredo Orgaz's definition of life, as cited by Roberto, which posits *life as an essential precondition for personhood's quality* [11], and the assertion by Günther Jakobs [12] that *the primary value lies not solely in life as a biological phenomenon but in its quality or supportability*. Regarding death, as elucidated by Gardiner and collaborators [19], the medical perspective defines it as the irreversible loss of consciousness and the capacity to breathe.

According to Arantes, ensuring the right to life entails *allowing death to approach us in the most tranquil manner possible. This is invaluable and should not be squandered* [23]. Furthermore, she elaborates:

(...) *because human dignity may go through the experience of surrendering. Of embracing our finitude consciously, as a profound aspect of human existence. So,* (...) *it is a human experience of extreme power, it is the greatest decision to surrender* (...) *to live one's finitude* [24].

Thus, the State must comprehend the right to life as inseparable from dignity, as the experience of living varies for each individual and can only be grasped when the dignity of every living person and the individual "quality" discussed by Jakobs [12] are considered, and even more so, if it allows for the right to death or the process of mortality to be experienced fully, as argued by Arantes [23]. In this regard, concerning the essence of this article, when there is a diminishment of dignity and quality of life, the right to life is probably not present.

Brazilian society's myopic view on the finite nature of life

Brazilian society lacks the maturity to engage in discussions about finitude, often exhibiting a myopic perspective or overlooking the inevitability of death, despite it being an undeniable reality that life is ultimately a journey towards mortality. This reality, coupled with the phenomenon of population aging and advancements in medical science, should prompt society to take a keen interest in exploring the concept of finitude.

Over the past few decades, medicine has made significant strides in the field of thanatology, particularly when it comes to the core of palliative studies. Yet only one in ten people in the world receives palliative care [25]. It is crucial to highlight the lack of comprehensive regulation surrounding palliative care, with minimal legal frameworks addressing the issue, exemplified by CFM Resolutions 1,805/2006 [26] and 1,931/2009 (Code of Medical Ethics) [27].

Notably, CFM Resolution 1,805/2006 was subject to legal scrutiny through Public Civil Action 0014718-75.2007.4.01.3400, initiated by the Federal Prosecution Office at the Federal Regional Court of the First Region, in the Federal District [28]. Initially, the prosecution contended that such a resolution could be interpreted as authorizing euthanasia, a viewpoint that was dismissed by the court's ruling, which acknowledged that the practice of orthothanasia aligns with the principles of the Brazilian legal system.

Moreover, in the state of São Paulo, Law 10,241/1999 [29] provides for the rights of health service users to provide informed consent or refuse procedures, decline painful or extraordinary treatments, and designate their place of death. Recently, this law was compiled and replaced by Law 17,832/2023 [30], which fully retains its content. This legislative measure has empowered patients in São Paulo to make decisions in a free, voluntary, and well-informed manner, representing for many the foremost legal framework addressing finitude with meticulous regard for patient autonomy and preferences.

Considering the evident discomfort within Brazilian society concerning the acknowledgment of finitude and individuals facing terminal illnesses or incurable conditions, alongside the reluctance to engage in discussions on these matters, this article underscores the imperative to confront such issues. This hinges upon the explicit regulation of practices on end-of-life care and aims to shed light on the right to a dignified death.

"Thanasias" and the finite process of life

Given the comprehensive discussion and the significant concerns raised, definitions and practices that may constitute part of the process of dying will be briefly provided—that is, euthanasia, assisted suicide, mythanasia, dysthanasia, and orthothanasia.

Euthanasia, from its philological roots, means a "good death," that is, one devoid of suffering. Its implementation involves actively terminating an individual's life due to their condition of extreme and unbearable suffering [31]. It can take on a commissive form, involving active medical intervention, or an omissive form, where acts considered ordinary for life maintenance, such as feeding, hydration, preventing choking, or hygiene, are withheld.

Presently, this practice is regarded as a form of privileged homicide under the Brazilian Penal Code [17] (Article 121, §1), contingent upon establishing its significant moral value and obtaining the patient's consent. However, it is legally approved in certain countries, including the Netherlands, Belgium, Luxembourg, Switzerland, Colombia, and Canada.

Assisted suicide involves medical assistance in providing a substance capable of ending life, which the patient self-administers through injection or ingestion, without direct participation from the physician. In Brazil, such practice is classified as the criminal act of inducing, instigating, or aiding suicide or self-mutilation (Article 122 of the Penal Code [17]).

Rooted in Greek, the term "mythanasia," conveys a sense of a miserable death and pertains to a situation where, unlike euthanasia and assisted suicide, death occurs not by the individual's choice but due to structural social factors. It encompasses the omission of structural support, often justified by limitations within the public health system under the guise of the "reserve of the possible." It also occurs when, despite entering the healthcare system, the patient becomes a victim of medical error or substandard medical practice [32].

Dysthanasia, derived from Greek roots meaning "painful death," describes a protracted or excessive delay in death [33]. It is characterized by the obsessive preservation of life through extraordinary means that do not alleviate the patient's existing health condition. According to Diniz [34], it embodies *the undue prolongation of the dying process of a terminally ill patient or the imposition of futile treatments, aiming not to extend life but rather the process of dying*.

The practice of dysthanasia should not be viewed as contradictory to euthanasia, as there exists no principled, legal, or ethical justification for artificially prolonging life beyond necessity. There is no obligation to subject patients or their families to dysthanasia; in fact, such practices often exacerbate suffering and may intensify the patient's pain. Currently, dysthanasia is not classified as a criminal offense in Brazilian law, yet it is proscribed by the Code of Medical Ethics [27].

Orthothanasia, derived from Greek roots meaning "good death" or "death at the right time," embodies the concept of allowing individuals to pass away naturally, according to the inherent process, without hastening or unduly prolonging life [34]. The objective of this medical approach, endorsed by CFM Resolution 1,805/2006 and the Code of Medical Ethics [27], is not to terminate life but to ensure that it is experienced most optimally, even amidst the journey towards finitude. The underlying principle is to facilitate a peaceful approach to death, minimizing pain and suffering as much as possible.

Orthothanasia is strongly associated with palliative care, a term stemming from the Latin word "*pallium*," meaning "cover" or "protection against adverse conditions." In line with this, Arantes [24] asserts that providing palliative care entails shielding patients from the detrimental effects of their illness and alleviating the suffering caused by a progressive disease. From the outset, it is appropriate to say that orthothanasia aligns with fundamental rights when conducted consciously and comprehensively for all individuals, ensuring the absence of suffering, and fostering a dignified coexistence with the process of dying.

Principles that deal with finitude

As discussed by Roberto [11], Alfredo Orgaz advocates that life is more than a subjective right but rather a precondition for the establishment

of individual quality, publicly safeguarded and independent of individuals' volition, rendering individual consent ineffective in altering this guardianship.

Consequently, the right to life is deemed non-negotiable, not categorized as a first-generation right but rather as a form of public guardianship. However, the precarious aspect of this assertion lies in the potential for abuse by the State when the right to life is entirely under its protection. Observing the right to life as a matter of public guardianship leads to a conceptual framework akin to Hobbes'[35] contractual definition of society, wherein individuals surrender all freedoms—including the right to life—to the State, leaving only the sovereign as the absolute free entity.

Contrarily, Locke's[36] perspective seems more fitting for democratic governance, as it acknowledges that only a portion of individual freedoms is relinquished under the social contract, thus preserving the right to life from complete transfer to the State. In navigating this dichotomy, Dias' viewpoint is notable, emphasizing that *individuals, regarded as subjects of rights rather than objects subject to state or third-party intervention, constitute the core of all fundamental rights and warrant unconditional respect as such*[37].

In essence, the State lacks the authority to unilaterally dictate the protection of individuals' lives, as this right was never surrendered to it. The right to life serves as a foundational principle in the formation of the State and is, thus, beyond the purview of the social contract.

Miranda[10] contends that life is considered unavailable not solely because it is protected by the State, but rather because every right inherently entails a corresponding duty. In this context, the right to live also encompasses the duty to live, as otherwise, Brazilian law would sanction assisted suicide and euthanasia.

However, specific doctrinal perspectives posit that the right to life implies a corresponding right to death, recognizing that life transcends mere biological existence or legal protection. It necessitates an understanding of all the complexity the word entails, considering individual interpretations of life, its limitations, desires, quality, and continuity of its dignity, as elucidated by Jakobs[12] and Calsamiglia, as cited by Dias[13].

It is noteworthy to highlight authors advocating for the right to self-determination regarding one's own life, that is, the right to death. In his discussion on euthanasia, Dworkin[38] asserts that according to the principle of autonomy, individuals have the prerogative to decide for themselves about ending their lives, provided their decisions are not deprived of rationality. Similarly, Siqueira-Batista and Schramm assert that the right to freedom and *autonomy implies that everyone can directly control their own life and may choose death when they feel fully depleted*[31].

The principle of human dignity must be construed as the entitlement of individuals never to *be treated in a manner that undermines the inherent value of their own lives*[39]. In other words, to uphold this principle within the context of the dying process, it is imperative that each person is accorded due significance and that their conception of life is respected.

Still regarding freedom and life, Kant[40] underscores that if every rational being possesses a will, they inherently act in freedom—understood as the right to not be coerced by the choices of others. Consequently, human beings are deemed sovereign over themselves and possess the autonomy to shape their existence in any manner they see fit, including the decision to terminate their own life. Considering this clash of principles, it becomes apparent that the fundamental rights of individuals in the dying process are often disregarded or wrongfully enforced.

Palliative care, dignified death, and the limitations of the Brazilian State

As discussed, life is individual to each person and is a fundamental individual right, restricted only in the context of euthanasia and aid in dying. The government refrains from manifesting on all other aspects and situations related to the end of life.

With the advancements in medical science, palliative care emerges as the optimal approach for attending to patients nearing the end of life.

This choice not only addresses the medical condition but also ensures active consideration of patient preferences, providing hope to individuals previously marginalized by society. Arantes suggests that *the most ethical approach in palliative care is to heed the patient's wishes attentively* [24].

Within this care framework, it is feasible to manage the subject of death delicately, enabling patients to comprehend and acknowledge the process without enduring unnecessary suffering and at the appropriate juncture. This perspective is crucial in our societal context, underscoring the notion that life retains its essence even amidst the process of dying. Consequently, it is posited that a dignified death should not be considered a distinct entitlement but rather the final expression of life. Thus, the realization of a fulfilled life hinges upon the exercise of the right to a dignified death.

Brazil still has considerable progress to make concerning the development of primary healthcare and palliative care. Only when palliative care reaches maturity and is universally accessible can the government entertain discussions surrounding the regulation of euthanasia. As Arantes elucidates: *(as a society) we are yet to attain the necessary maturity to engage in conversations about natural death. Let alone euthanasia or assisted suicide* [24].

Euthanasia is often perceived as a recourse for alleviating the immense suffering experienced by terminally ill patients. The crux of the matter lies not in the patient's choice between the inevitable finitude of life and insurmountable suffering, but rather in the availability of alternatives such as palliative care to mitigate suffering while acknowledging life's approaching end. Consequently, the discourse surrounding the regulation of euthanasia remains unattainable, with its criminalization often employed as a public policy measure to safeguard societal welfare [23].

Therefore, it is necessary to discuss finitude beyond the medical discourse, considering its social, legal, public health, and budgetary dimensions. However, these topics are too complex and extensive to be addressed within the scope of this article, as they warrant individualized study.

Final considerations

Death and finitude are entrenched taboos within Brazilian society, rendering the very process of finitude and dignified death invisible and neglected as subjects for societal discussion and confrontation. Owing to this dearth of discourse, Brazilian society lacks the social and civic maturity necessary to engage in conversations about death, its nuances, and its boundaries as the ultimate act of civil existence.

Given that death is an inherently natural occurrence affecting all living beings, the imperative for dialogues on this subject is underscored, particularly within the realms of sociology and law. Such discussions enable a deeper comprehension of the ethical, social, and legal dimensions of the topic, as well as its medical facets.

However, individuals in the throes of finitude, particularly within the legal sphere, are often disregarded and systematically rendered invisible, impeding the formulation of norms, comprehension, and societal awareness concerning the issue of death. Consequently, the Brazilian legal system lacks a specific legislative definition of "life," leading to variations in interpretation and application among different legal interpreters and concrete situations. Similarly, the term "death" and its legal implications suffer from a lack of express definition, resulting in varying interpretations and consequences in legal contexts.

This regulatory gap engenders detriment by impeding the cultivation of best practices and wholesome frameworks for end-of-life care. it is imperative to develop legal frameworks that transcend these limitations and provide more precise guidelines to facilitate the process of death. Such instruments should encompass delineating legal definitions of life and death, outlining practices within palliative care, mitigating the practice of dysthanasia, and regulating legal avenues for expressing one's final wishes.

Within the scope of public health, it is imperative to broaden access to essential care integral to the process of finitude, ensuring them as fundamental rights and advocating for positioning, research, training, and assessment to expand palliative care services. These enhancements presuppose the provision, by public administration, of appropriate settings to facilitate the support of the finitude process, thereby enabling dignified deaths for both terminally ill patients and those afflicted with incurable, progressive illnesses.

Within this framework, it is proposed that "life" be legally construed as the fundamental prerequisite for a person to be a 'person,' encompassing the biological phenomenon alongside a primary consideration—the quality or, at the very least, the supportability of self-sustenance. It is acknowledged that this quality and level of supportability vary according to each specific case. Likewise, it is suggested that "death" be defined as the ultimate eventuality for a living being, signifying the full exercise of the right to life and, in a medical-legal context, as the irreversible loss of consciousness coupled with the irreversible cessation of breathing.

Thus, only through an expanded discourse on death and the finitude process, the cultivation of social maturity, the assurance of dignified deaths, and the comprehensive implementation of palliative care, can the discussion concerning criminal protection for practices such as euthanasia and assisted suicide become both viable and justifiable.

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