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AUTONOMY IN ADVANCED DEMENTIA AND PERMANENT VEGETATIVE STATES IN IMMINENT DEATH

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ABSTRACT. Existential private autonomy, as an expression of the dignity of the human person, represents for the individual the possibility of acting in accordance with essential values and meanings for elaboration of their life project. The authors of this study, two occupational therapists, two lawyers and a psychologist gather their knowledge and dialogue to demarcate the relevance of existential private autonomy in conditions of advanced dementia, in permanent vegetative states and imminent death. In the task proposed, the authors pondered over their experiences and dialogues as professionals with a diversified academic background, inclined to provide spaces to communicate life and welcome pain. The legal bases of private autonomy are presented and discussed, as well as the assumptions of Viktor Frankl's Logotherapy in defense of freedom of will and dignity at the end of life.

Keywords: Autonomy; dignity; death.

AUTONOMIA EM DEMÊNCIA AVANÇADA E ESTADOS VEGETATIVOS PERMANENTES NA IMINÊNCIA DE MORTE

RESUMO. A autonomia privada existencial, como expressão da dignidade da pessoa humana, representa para o indivíduo a possibilidade de agir em conformidade com valores e significados eleitos essenciais na elaboração do seu projeto de vida. Neste estudo, seus autores, dois terapeutas ocupacionais, dois advogados e uma psicóloga, somam saberes e dialogam com intuito de demarcar a relevância da autonomia privada existencial nas condições de demência avançada, nos estados vegetativos permanentes e na iminência de morte. Na tarefa a que se propõem, os autores ponderam sobre suas experimentações e interlocuções enquanto profissionais de formação acadêmica diversificada, inclinados a ofertar espaços para comunicar vida e acolher dores. São apresentadas e discutidas as bases jurídicas da autonomia privada, assim como os pressupostos da Logoterapia de Viktor Frankl em defesa da liberdade de vontade e da dignidade no final da vida.

Palavras-chave: Autonomia; dignidade; morte.

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AUTONOMÍA EN DEMENCIA AVANZADA Y ESTADOS VEGETATIVOS PERMANENTES AL BORDE DE LA MUERTE

RESUMEN. La autonomía existencial privada, como expresión de la dignidad de la persona humana, representa para el individuo la posibilidad de actuar de acuerdo con valores y significados elegidos esenciales en la elaboración de su proyecto de vida. En este estudio, sus autores, dos terapeutas ocupacionales, dos abogados y un psicólogo suman conocimiento y diálogo con el fin de demarcar la relevancia de la autonomía privada existencial en condiciones de demencia avanzada, en estados vegetativos permanentes y muerte inminente. En la tarea que proponen, los autores reflexionan sobre sus vivencias e interlocuciones como profesionales con una formación académica diversificada, inclinados a ofrecer espacios para comunicar la vida y acoger el dolor. Se presentan y discuten las bases legales de la autonomía privada, así como los supuestos de la Logoterapia de Viktor Frankl en defensa de la libertad de voluntad y dignidad al final de la vida.

Palabras clave: Autonomía; dignidad; muerte.

Introduction

Regarding the life cycle, both dignified death and life are fundamental human rights recognized in our legal system. A dignified death is understood to be a death without pain, free from anguish and according to the will of the holder of the right to live and to die (Ribeiro, 2006). Ordinance 675/GM of March 30, 2006, of the Ministry of Health, approved the Charter of the Rights of Health Service Users, consolidating in a single document the rights and duties of exercising citizenship in health throughout Brazil, defending the interest of the person under health treatment, as well as the user's free, voluntary and informed consent or refusal, after adequate information, to any diagnostic, preventive or therapeutic procedures, unless such occurrence entails a risk to public health.

Therefore, users have the right to have their special needs identified and met so that they can have quality of life. Therefore, ethical, clinical, social and psychological issues, among others, must be considered (Bromberg, 1998). On the other hand, researchers (Kovács, 2008; Cano et al., 2020; Lourenção & Troster, 2020) argue that health professionals, in the different stages of their training process, should exercise their right to an education for death, mature their practices in order to guide their interventions to soften the departure of those under their care, to position themselves with a humanized, autonomous and responsible attitude in the face of the death of those who demand to have their suffering legitimized.

In this perspective, there is a need to share experiences and reflect on everyday issues that bring discomfort in their essence, a noise that goes beyond the technical limits on the management of death and dying. The emergence of feelings and subjectivities constituting the practice scenarios is evidenced in the sharing of ways of acting, while developing personal and interpersonal skills (Heringer, 2012; Morais, Castro, & Souza, 2012; Morais & Souza, 2016).

In favor of the dignity of the human person and in a mobilization for this integrative experience of sharing knowledge, dialoguing and reflecting on the subject, this study emerged, aiming to problematize private autonomy in conditions of advanced dementia and permanent vegetative states in the imminence of death under the interdisciplinary perspective. For this, two occupational therapists, two lawyers and a psychologist participated in this construction, being designated as a ‘space for dialogue’ the virtual environment where the text took shape and deepened reflections.

As a starting point for dialogues and reflections between these professionals, the monograph presented in the Graduate Program in Civil and Civil Procedural Law at Fundação Getúlio Vargas in Rio de Janeiro, entitled *Testamento vital e sua (im)possibilidade no ordenamento Jurídico brasileiro* (Aita, 2018), which dealt with the legal bases of private autonomy. The assumptions of the Viktor Frankl’s Logotherapy were also considered, in order to broaden the debate about the interventions of members of intermediary entities and individuals in individual freedoms (Teixeira, 2018).

Private autonomy in advanced dementia and persistent vegetative state on the verge of death

Death puts an end to human existence and all its potentialities: this is the anguish of being mortal, while survival functions as the only possible contrast to the biopsychic decline. Nobody escapes death. It is a gradual process that begins before the disruption of organic fullness. Dying does not antagonize living: it integrates the very essence of life. Therefore, the law must not only discourage conduct contrary to prolongation of life, but also severely punish those who try to shorten it, and the role of legal norms is to promote and support conduct that respects the right to experience the end of life with dignity, as expression of the idea that “[…] every body is worth the pleasure of being mortal” (Assumpção, 2018).

The Brazilian Constitution of 1988 (art. 1, III) radiates the dignity of the human person to the legal system, whose content re-signified the bases of private autonomy. Applied to the context of existential relationships, the exercise of private autonomy implies that “[…] fundamental decisions in a person’s life, especially existential ones, should not, as a rule, be imposed by a will external to them” (Olivieri, 2013, p. 2), as well as representing the power of self-government by which the person must do what they understand best for themselves, “[…] mainly with regard to decisions concerning themselves, their body, their individuality, as long as their action is responsible, who have full information about the effects of their actions” (Teixeira, 2018, p. 96).

The discussion is especially relevant when it comes to people in a persistent vegetative stage, advanced dementia and imminent death. In this context, the American Society for Euthanasia proposed, in 1967, an “[…] anticipated care document, through which the person could register their desire to discontinue life-sustaining medical interventions” (Emanuel & Emanuel, 1990, p. 10). However, it was only in 1991 that the *Patient self-determination act* was edited, which became the global normative framework on the subject, influencing other countries, such as Spain in 2002, Argentina in 2009 and Portugal in 2012, to enact their regulations.

Advance directives are a general term encompassing instructions about medical care given to people who are unable to freely and consciously express their will, even if due to a transitory situation. There are two kinds of documents: the durable power attorney and the living will. The durable power attorney is the granting of powers from the incapable patient so that a third party can make decisions, not being the direct manifestation of their will, leaving aside the discussion of this institute. The living will is the document by which the person, in full possession of their abilities, disposes of the medical-therapeutic procedures that will be administered to them if unable to express their will, by means of a written document, which may be public, that is, notary-registered, or private (Dadalto, 2019).

The living will divides into two types the medical-therapeutic procedures that the person may or may not have: ordinary or extraordinary procedures. Treatments considered ordinary are those that are mandatory, given the high degree of benefit in reducing suffering and increasing the patient's quality of life. The extraordinary procedures, on the other hand, prolong life without significantly altering the terminality situation. Despite the original understanding that the living will can only fall on treatments considered extraordinary, such a limitation does not exist in Brazil, given the lack of regulation on the subject, thus creating the duty of reading the institute in the view of article 15 of the Civil Code, which states that "[…] no one may be compelled to submit, at risk of life, to medical treatment or surgical intervention".

Regarding the absence of an integrating system between notaries' offices and health sectors, it is essential to be prudent when attaching the aforementioned document to the medical record. As for the revocation, it is understood that this can be done at any time and in any form, as long as it is clearly stated. However, the physician accompanying the case is guaranteed the right to not comply with the guidelines written by the person, pursuant to resolution. 1931 of the Federal Council of Medicine, which allows it to refuse to practice acts contrary to their ethics. Hypothesis in which the professional will be replaced with another of equal competence.

Pillars of the Viktor Frankl's Logotherapy: the freedom of will, the will to meaning and the meaning of life

Viktor Emil Frankl, an Austrian psychiatrist, was the creator of Logotherapy and Existential Analysis, the first also identified as Meaning-Centered Psychotherapy. In 1950, he created the Austrian Medical Society for Psychotherapy, becoming its first president. Based on a series of lectures he gave, he wrote the book Homo *Homo patiens versuch einer pathodizee*, in which he discussed how to comfort and support people who are in extreme suffering, even under dire conditions while imprisoned in concentration camps during World War II. By problematizing these questions, he finds his central thesis about the meaning of life and human psychology (Frankl, 2016).

According to Frankl (2016), Logotherapy concepts are: 1) Freedom of will: meaning that man is always free to take an attitude; 2) Will to meaning: understood as the basic motivation of every human being; and 3) Meaning of life: life has meaning in every circumstance. Even in the face of suffering, death or conditioning factors - such as a disease with no therapeutic possibility of cure - we are free, responsible and we can choose how to position ourselves in these situations.

As highlighted by Carrara (2016), one of his relevant contributions concerns the discovery of the will to meaning, "[…] considered not only a 'secondary rationalization' of instinctual impulses, but a primary motivation (Frankl, 1985, p. 69, author's emphasis)". The will to meaning has an intimate relationship with the possibility that every human being has to decide and respond to the cry of life. Meaning cannot be created, it is authorial and must be found in the world and not in the subject who experiences it (Frankl, 1990, 2003). The freedom of will is the freedom to choose the attitude we adopt in the face of the constraints and circumstances that life presents us with. An intrinsically human characteristic, which is opposed to what Frankl calls pan-determinism: "[…] a view of the human being that discards their ability to take a position in the face of whatever constraints they may be" (Frankl, 1985, p. 86).

It is noteworthy that in the theoretical system of logotherapy (Frankl, 2016; Pereira, 2017), man is a multiple unit, composed of several aspects and presenting three main dimensions: somatic, which health professionals with their biological vision of man they propose to meet; the psychological dimension (psychodynamic logic of unconscious wishes, drives, constraints, instinct); and the noetic (spiritual) dimension that appears as the difference between human beings and other beings. It is in the noetic dimension that freedom of choice operates in the face of existence, since, being attracted by values and not just driven, man has to choose which possibilities to carry out or not, which paths to trace and what to become.

Reflections on the principle of human dignity

Suffering and the proximity to death make the patient reevaluate their life, evoking essential values (Américo, 2012; Aitken, 2012). However, even at this stage of the life cycle, they are free to make choices, purposes and find meanings.

In conditions of advanced dementia and permanent vegetative states, advance directives of the will are able to guarantee private autonomy, granting freedom of choice. As the clinical state deteriorates, biopsychic conditionings are intensified and, although there is a concomitant decline in cognitive functions, the noetic dimension remains intact. Faced with this vulnerability, efforts must be directed towards the construction of their biography in its most differentiated forms of expression, to promote the encounter of the meaning of the moment until the ultimate meaning is revealed.

The human is, and therefore must be respected and considered. A body and mind in decline do not mean the decline of the human in its noetic dimension. If the future is uncertain, the past can be eternalized and the present updated in genuine and meaningful encounters.

The spaces for welcoming the singularities of listening and talking about the processes of death and dying prove to be powerful resources in different theoretical perspectives of understanding the human, in and through which the challenges that are posed to professionals who enter them emerge. In these spaces, theoretical-practical approaches promote reflections on the exercise of human dignity and allow us to observe how much the routine of the multidisciplinary team – organized exclusively with a focus on disease control – opposes the principle of users' private autonomy.

It should, however, be noted that studies defend that the concept of autonomy is closely related to that of dignity. In these, there is the understanding that each man has his dignity and this is constituted as a product of his own acting in the face of the free choice of his behavior, in his social recognition and claim of respect as a favorable response to these choices (Teixeira, 2018, Dadalto, 2019).

Regarding dignity, Zirak, Ghafourifard and Mamaghani (2017, p. 49, our translation) clarify that:

> While dignity was the top priority, there have been a number of recent studies reporting the lack of respect, privacy and dignity in healthcare settings. Some studies point out that patients are vulnerable to the loss of their dignity in hospitals, but what threatens patients' dignity has been little investigated.

In a study carried out with patients with non-oncological chronic diseases in the imminence of death and using the *Patient dignity inventory* (PDI), Chochinov et al. (2016) observed that the loss of dignity was perceived as an attack on the personality, a diminished sense of worth, a feeling of being a burden to family members and people close to them, having unfinished business, worrying about the future, while expressing dissatisfaction with the past also associated with symptoms of fatigue, constipation and weakness, which tend to aggravate the loss of autonomy and increase physical dependence.

In Brazil, there is no public policy that guides end-of-life care, but isolated initiatives that, in general, tend to be expensive, conceived by users, as well as by the family members who accompany them, and of poor quality (Frossard, 2016). A social maturation is needed in this sense, which promotes comfort and the good management of pain and suffering to those who need care at the end of life (McDermott, 2019; Boles, 2021), a stimulus to the rediscovery of the meaning of being alive, all the days.

In this sense, Teixeira (2018, p. 75) considers that

> “[…] existential decisions, therefore, are only legitimate when taken by the holder themselves, as long as they are informed and aware of their act, as well as its consequences. Therefore, the projections of subjectivity in the shared spaces of intersubjectivity must be defined by the person”.

It is worth emphasizing the fact that, as a being influenced by psychophysical. optional constraints (Frankl, 1977, 1985, 1990, 2016), the user, under the conditions discussed here, is and remains free. This theoretical perspective is in line with the legal-dogmatic understanding that states:

> […] to make dignity real is to give each person the broad freedom to build their own life, fulfill their needs, make their choices and adone-se themselves with their existence, directing it in the way they understand that brings them greater fulfillment, because the conceptions of each one must be considered, since all values are possible in the Democratic State of Law, which, as seen, has pluralism as one of the fundamental pillars (Teixeira, 2018, p. 80-81, author’s emphasis).

Therefore, we believe that we have characterized the central foundations of the principle of human dignity in the search to support the reader with the conceptual assumptions and their ethical particularities.

Final considerations

When searching our awareness of the fact that it is essential that professionals in the health and human areas are available to deal with death, a question immediately emerges: Thanatology should be presented as a possibility to every person during their training process, since the death is a constitutive part of the life cycle.

It was a consensus that thinking about people with advanced dementia, persistent vegetative state or imminence of death brings with it theories of great complexity, which should be studied, debated by professionals with different methodologies and languages. We consider that in this dialogue one must consider the inferences of the common sense of uselessness or disinvestment that characterize discrimination and can be manifested through subjectivities. Failure to observe these aspects can cause physical, psychological and social suffering not only to users, but also to their families/caregivers and the team of professionals.

Challenging yourself to broaden the view, stimulate approximations of those who constitute care and, as such, are immersed in a society that denies death, ensures users a humanized approach and tends to improve the end-of-life experience with an emphasis on their quality.

The guarantee of good practices offered to people with advanced dementia, persistent vegetative state or imminence of death is based on the understanding that they are free to carry out, personally or through representation of their tutors, the decisions regarding their therapeutic plan.

In view of these reflections, it is essential to understand that the user in this condition is a subject of values, with the fundamental right to the freedom of will that is supported by the Brazilian legal system, as long as it is not in conflict with the rights of third parties.

Therefore, it is urgent to review the meaning of caring, to think exhaustively about the reason why we are inserted as professionals in this context of action. In this way, perhaps, we can dignify ourselves with the person in a painful experience, full of suffering and in search of a meaning for it.

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