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# Terminality Advance Directives and Nursing Practice in Brazil: Bioethical Issues

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## Abstract

Advance directives (ADs) are understood as the act of deciding what care the patient wants to receive in the period before death. Preserving the patient's autonomy by choosing his care guarantees human dignity during the process of dying. In Brazil, life expectancy and supportive technologies have increased, leading to growth of the number of terminally ill patients. However, there is still no legislation regulating ADs causing legal uncertainty in health professionals. Nursing professionals have the support of the Federal Nursing Council to respect the ADs, but, because it is an issue little explored, nursing professionals do not feel safe in the use of ADs, and changes in the curricula of the undergraduate courses in nursing are extremely needed, ensuring that patients have their wishes met during the dying process. Thus, this chapter deals with bioethical and legal issues involving ADs and nursing in the Brazilian context, proposing to deepen reflection and criticism on the issue and subsidies for decision-making.

**Keywords:** advance directives, right to die, palliative care, bioethics, nursing

## 1. Introduction

Life in the society is shaped by a set of principles, values, and concepts that determine approval or disapproval judgments in the interpersonal relationships and actions of the individuals. In this context, ethics seeks to reflect and understand the presuppositions of morality, aimed at achieving the best result for people and society [1].

However, this concept was expanded through scientific and technological advances, emerging bioethics in the 1970s, which means "ethics of life" in the literal sense. Bioethics proposes the dialog between the biological and human sciences. In 1971, the oncologist and university professor Van Rensselaer Potter published the book *Bioethics: A Bridge to the Future*, placing bioethics as necessary to ensure human survival in the accelerated civilization development. He reported that knowledge has been acquired at a speed far greater than the capacity and ability to know what to do with it [2].

Bioethics needs to be considered not only in the research and development area but also in interprofessional relationships in health, not limiting the analysis of such relationships only to deontological codes. In this sense, the North American principlist model is shown as a good ally in directing actions, reflections, and decisions of health professionals [1].

The beneficence, non-maleficence, autonomy, and justice principles can be applied *prima facie* in health decision-making. Beneficence suggests the need to do good, requiring professionals' knowledge and skills to distinguish which procedures and practices are beneficial and which can harm. Non-maleficence is not exposing the patient to risk situations, minimizing damages, and seeking other alternatives. Autonomy represents the patient's right to decide what is done to his body and health, based on his life purpose, principles, and creed. The principle of justice is the social duties and benefits, which are contemplated and guaranteed in the Federal Constitution of 1988 and in the Organic Law of Health (Law 8080/90) [3].

In different healthcare settings, terminality is a topic full of ethical dilemmas that require decision-making by the professional who is always trying to overcome death and interfere in different ways in this process. As death is still a "taboo" in our society, when it occurs in health services, it becomes more evident as a medical failure than the simple understanding of the natural course of life, leading to bioethical discussions and problems [3].

Facing the current conjuncture of advances in technological development for the extension of life, death previously seen naturally and as part of the process of human finitude is now tried to be avoided. At present the usefulness of life support therapies is questioned, such as: When to interrupt or maintain life without hurting the principles of bioethics? [4].

The problems revealed with end-of-life care express the importance of intensifying the debate about the imminence of death and human terminality, analyzing the progress of the social behaviors and the ethical precepts of health professionals in palliative care [5].

In this context, the theme of the advance directives (ADs) has been discussed in Brazil, which consists of deciding what care to receive in the period before death, ensuring to the patient more dignity and quality in this process. Refusing unnecessary interventions, pain and suffering relief, and home care around the family rather than hospital isolation are debatable issues that express the patient's autonomy.

Therefore, legal issues of effectiveness of the social rights and the affirmation if they contemplate the fundamental rights of the constitutional legal order expressed by the Democratic State of Law will be addressed, with due guarantees and legal safeguards of the existential minimum or the possible reserve, accessibility to justice as a common good.

Thus, this chapter addresses the bioethical and legal issues involving ADs and nursing in the Brazilian context, proposing a deepened reflection and criticism on the topic and subsidies for decision-making involving the nursing professional.

## **2. Advance directives and nursing**

Brazil is following the world trend with a significant increase in the population over 65 years old, from 4.1% in 1991 to 7.4% in 2010. In 2020, it is assumed that Brazil will be sixth worldwide, considering the older adult population [6].

In this context, the increase in life expectancy and in the supportive technologies has led to a substantial increase of terminally ill patients. During the terminality of life, the individual is faced with unusual events and arduous decisions regarding

health care, including communication of bad news, palliative care, advance directives (living will), order of not resuscitating, and dysthanasia [7].

Little is prepared for death. Even the health professionals are prepared to seek only life above all, putting death as something to be defeated [8]. In the situations where the medical behaviors are exhausted, the palliative care appears to offer better assistance to the patient and to minimize the suffering [9].

Biologically, death is a consequence of the vital functions, cardiac and respiratory end, and over the years, even feared, it has been postponed through the use of various technologies. Cardiopulmonary resuscitation (CPR) in some cases keeps the heart pumped only for a short period turning into an invasive and traumatic experience and sometimes depriving the patient of their choice of death that can lead to a loss of dignity and prolongation of suffering [10, 11]. Thus, the question is: What benefits are added to the state of human existence in which the person does not establish more relationships with other people, as in the case of the state of coma? Why increase the days of life, concomitantly, to the affliction of the patient and their relatives? [3].

Under some conditions, the decision to maintain life at any cost must be taken by the patient, because although death is relatively close, he is still alive and conscious, and his wishes must be respected as far as possible [12]. The act of deciding what care to receive in the period before his death guarantees more dignity during the process of dying [13] since the bioethical principle of autonomy can interfere, question, and choose procedures or treatments [3].

In the meantime, it is worth noting that the principle of autonomy foresees that decision-makers are rational agents with appropriate cognitive conditions for the understanding of their own interests and without any external controlling influences. Thus, the obligation to respect the autonomy of the patient can exceed the duty of beneficence of doctors and health professionals, if rationality and knowledge of the patient's situation can be confirmed [14].

Also a greater vulnerability of the patients with chronic neurological-incapacitating conditions should be considered, such as Parkinsonism or muscular dystrophy. In these cases, it is important to create a formal communication process, from the diagnosis of a serious illness. For neurology patients, the period between the diagnosis and the loss of communication capacity is frequently limited, and the opportunity of effective communication in this period should not be missed [14].

Under the view of humanization, the technical-scientific advance restricts the patient, since health care is directed to attend only biological and physiological aspects. Thus, ADs enable patients to express the subjectivities of their desires and, with dignity, to direct what they expect for their days to the end of life.

These advances have enabled some patients to survive in persistent or minimally conscious vegetative states for decades. In these cases, due to emotional issues, the caregivers opt for care continuity. However, such decisions have impacts on the patient's quality of life and ethical responsibility for the distributive justice of health systems. Doctors are encouraged to make decisions in individual cases since conflicts may be unavoidable. In cases of some conflict, doctors may ask help to nurses as they are professionals who are with patients most of the time, being potential experts of their wishes [14].

Given such conditions, advanced care planning (ACP) strategies have been discussed in India, ensuring that adults at any age or stage of health understand and share their personal values, life goals, and preferences regarding future medical care. In this context, the main responsibilities of neurologists in medical practice in end-of-life care appear in two situations: catastrophic brain injury (CBI) and life-limiting neurological illness (LLNI). Patients with CBI are hospitalized in an altered mental status, and life-sustaining treatments (LST) are often performed



immediately after. Also the difficulties of decision-making for not presenting legislation on the declaration of death by neurological criteria were pointed out, recommending that the medical team makes decisions, in conflicting cases, in consensus with the relatives and other members of the health team [14].

In Brazil, as being a very recent topic, there is little research that explains the ADs and the understandings of health professionals and society on the theme [15].

Currently, the consideration for the patient autonomy is being discussed, as well as the power to express opinions, make decisions, and proceed according to their personal principles and rules [16]. This right is shown in Article 15 of the Civil Code and Articles 22, 23, and 24 of the Code of Medical Ethics (CEM).

In the world context, ADs appeared in the United States in the 1960s and were initially presented by the American Society for Euthanasia in 1967 through the document entitled “Living Will (TV),” in which the individual could register their wishes to cease the medical conceptions of continuity of life [17].

It is suggested that advance care planning initially includes information about the types of life-sustaining treatments available and decisions about the types of treatment that patients would or would not want if they were diagnosed with a life-limiting illness. Afterward, it is necessary to encourage the sharing of personal values by patients and their families, and only then the ADs should be written, expressing what kind of treatment they would like or not if they could not speak for themselves [18].

If the patient does not have the cognitive conditions to decide, it is suggested that the substitute decision-maker meets the following criteria: being able to make a decision, being available and willing to do so, and being legally established as representatives of the patient. In the absence of a legally established representative for decision-making, the next of kin may be considered a substitute [18].

In Brazil, from the juridical point of view, in the current Constitutional Order, principles are considered as guidelines, and unlike the norm that regulates an end, the principle regulates a means, and it is the foundation of any legal system. In the case of ADs, the principles seek to eliminate gaps, offering coherence and harmony to the legal order. Although widely discussed worldwide for years, the ADs were inserted in the national healthcare scenario only in 2012, through Resolution CFM 1995/2012 which guides the medical practice in end-of-life conditions, ensuring patient’s self-sufficiency and the preservation of human integrity [19].

According to the CFM, the ADs are characterized as a grouping of wills, clearly expressed by the patients about their treatments and care they want to receive when they are unable to manifest their wishes [19]. This resolution considers the probability of the patient to name a representative so his demands can be met when he can no longer pronounce them [19]. The instruction to interrupt treatments that unnecessarily prolong the life of the patient with a severe or incurable illness allowed to the doctor was already provided for in Resolution CFM 1805 of 2006 [20].

When talking about ADs, it is essential to understand that this is the junction of the Durable Mandate (DM) and TV in a single document [17].

The DM is the patient’s indication of one or more attorneys-in-fact to be consulted by the medical team in case of his definitive or momentary impossibility when it is necessary to make a decision on the treatment or not treatment [16]. The TV is a document in which the patient details the treatments and procedures he intend to do or not to do when he is incapacitated to manifest his will, being useful only in cases of terminality [16].

The TV is a legal instrument that enables to certify the domination of the individual in the decisions about his health, having the “good death” as his final purpose [19].

Brazilian doctors still do not have legal support in relation to the ADs. However, they must obey CFM Resolution 1995/2012 [16]. The doctor should transcribe in

medical records the ADs that are formally declared by the patient. If the person in the hospital is not known and if there is no appointed attorney-in-fact, available relatives, or concordance between them, the doctor should refer to the Bioethics Committee of the institution. If there is no committee, the hospital's Ethics Committee or Regional and Federal Council of Medicine needs to document their opinion on ethical confrontations, when considering this measure as indispensable and appropriate [19].

Currently, the Bill 149 of 2018 is in process in the Brazilian Federal Senate, which regulates the advance directives on health treatments. The Article 2, paragraph I of this Bill defines ADs as a "manifestation documented by public deed, without financial content, of the will of the reporting person to receive or not certain medical care or treatment, to be respected when the person can not express his will, freely and autonomously" [21].

Also in Article 3, the Bill proposes that "every greater and capable person has the right to declare in advance, his or her will to receive or not certain medical treatments in the future when being in clinical condition" [20]. Article 5 of this same Bill reports that "advance directives must be met by health professionals and public or private health services, as well as by relatives, legal guardians, and the declarant's representative" [21].

The respect for the independence of the actions related to the ADs is an important benefit for their application, especially in the disease termination, not only for doctors but also for the nurse [22].

ADs are seen by nursing professionals as synonymous with attending to the principle of autonomy of the patient and their relatives, with undeniable character and with inevitable growth [23]. It is an instrument capable of facilitating decision-making on ethical issues related to the end of life [24].

Nursing is recognized as the professional category that plays a primary role in the exercise of the right to self-determination, helping and facilitating patient decision-making, as it is present throughout the death process [25]. When establishing effective and early communication with the hospitalized patient, the nursing team creates a bond of trust between patient and professional that allows the conscious and autonomous exercise of the right to self-determination, ensuring that the patient's wishes and choices are taken into account in situations involving decision-making in terminality [26].

The Code of Ethics of Nursing Professionals [26], in its Article 42, Sole paragraph, describes that the nursing professional must "Respect the person's advance directives regarding the decisions about care and treatment that he or she wishes or not to receive at the moment when he/she is unable to freely and autonomously express his/her wishes."

However, the lack of knowledge of regulations aimed at nursing professionals and the fear of ethical-legal implications interfere with the use of ADs. Faced with this reality and to avoid conflicts, nurses prefer to attend the wishes of family members, even if these wishes are not in accordance with the wishes expressed by the patient [27, 8].

For nursing professionals to feel effectively supported and safe in the use of ADs, it is necessary to include this subject in the curricula of the Nursing Undergraduate Courses, and the dissemination of scientific knowledge should be in agreement with the benefits brought to the patients with their wills met.

Currently, the National Curricular Guidelines of the Nursing Undergraduate Program indicate that nurses' training should cover issues related to the prevention, promotion, healing, and rehabilitation of the health of individuals and the community. Thus, higher education institutions guided by these guidelines offer technical-scientific training that favors therapeutic obstinacy, aiming only at maintaining life at any cost [28].

It is believed that curricular changes, which deepen the ethical debate around issues related to the dying process, are necessary in the training of the nurse since the proximity of the nursing team with the hospitalized patient provides emotional exhaustion, and these professionals feel they are helpless before death. It is necessary that the process of dying be debated within educational institutions, so future nursing professionals understand and respect terminality as a phase present in human existence [23].

Rethinking treatment related to terminal patient care within higher education institutions favors the reduction of difficulties in dealing with the death process and therapeutic obstinacy and providing more humanized care [29].

Thus, it is important that the future nurse be encouraged to know the ADs during the professional training process, to understand its applicability in their clinical practice and to stimulate its use by patients, terminal or not, informing the possibility of construction and the importance of the ADs and presenting the necessary explanations for the elaboration of a document of this nature [28].

### **3. Conclusion**

In Brazil, there is still no legislation that deals with ADs, which makes this topic little debated and diffused among health professionals, more specifically among the professionals of the nursing team.

Guaranteeing the individuals the right to carry out their wills in terminality through the ADs is still not enough since collective work is indispensable and necessary to respect their autonomy and reflections on the cultural actions of professionals' health and family members that determine the paradigm of sustaining life at any cost.

The main challenge found during the dying process is to ensure that in practice, the patient's wishes are met. It is noticeable that the implications and obstacles resulting from the ceaseless transformations of the right to health as a whole are far from over, especially the relationships inherent to the principle of human dignity, individual freedom, and the practices of health professionals.

There is a need to disseminate among nursing professionals the importance of encouraging the free and informed autonomy of patients and of the Federal Nursing Council regulation that supports professionals who respect the ADs of the individuals under their care. The knowledge of the Code of Ethics of Nursing Professionals and the inclusion of ADs in the curricula of Nursing Undergraduate Courses are essential for Brazil to make a positive contribution to this issue.

In view of the current Brazilian health scene, the ADs are characterized as a new subject, and its applicability involves cultural change, family and health professionals' agreement, and an early approach in both undergraduate and care education.

### **Conflict of interest**

We declare there is no conflict of interest in this research.

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