ADVANCE DIRECTIVES: CHALLENGES AND PERSPECTIVES AMONG MULTIDISCIPLINARY HEALTH CARE TEAMS IN BRAZIL

DIRETIVAS ANTECIPADAS: DESAFIOS E PERSPECTIVAS ENTRE EQUIPES MULTIDISCIPLINARES DE SAÚDE NO BRASIL

DIRECTIVAS ANTICIPADAS: DESAFÍOS Y PERSPECTIVAS ENTRE EQUIPOS MULTIDISCIPLINARIOS DE ATENCIÓN EN SALUD EN BRASIL

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ABSTRACT

Technological advancements in medicine, by prolonging life, have generated complex ethical dilemmas related to finitude, highlighting the need to ensure patient autonomy in the dying process. This chapter, based on a master's dissertation, aims to analyze the perspective of the multidisciplinary healthcare team on Advance Directives (ADs) and Living Wills (LW) in Brazil. The qualitative research employed semi-structured interviews with 21 professionals (nurses, physicians, and psychologists) from a teaching hospital, whose data were subjected to content analysis (Bardin, Minayo). The results revealed four thematic categories: 1) Professionals' understanding of patient autonomy, which, although conceptually clear, faces difficulties in practical application due to a lack of patient information and medicine's curative focus; 2) Professionals' experience with terminally ill patients and family involvement, marked by conflicts between patient and family wishes, with family will often prevailing and late

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referral to palliative care; 3) The perception of the precarious insertion of ADs in Brazil, due to a lack of guidance, widespread unawareness, absence of robust legal regulation, and professional insecurity; and 4) Professionals' knowledge of Living Wills, which proved incipient and confused, limiting its effective use in clinical practice. It is concluded that the implementation of ADs and LWs requires a profound transformation in the training and continuing education of healthcare professionals, as well as the promotion of open dialogue and a clear legal framework, aiming to guarantee the dignity and respect for patient autonomy at the end of life.

Keywords: Health Education. Healthcare Professionals. Patient Autonomy. Advance Directives. Living Will. Palliative Care.

RESUMO

Os avanços tecnológicos na medicina, ao prolongarem a vida, têm gerado complexos dilemas éticos relacionados à finitude, evidenciando a necessidade de garantir a autonomia do paciente no processo de morrer. Este capítulo, baseado em uma dissertação de mestrado, tem como objetivo analisar a perspectiva da equipe multidisciplinar de saúde sobre as Diretivas Antecipadas de Vontade (DAV) e o Testamento Vital (TV) no Brasil. A pesquisa qualitativa utilizou entrevistas semiestruturadas com 21 profissionais (enfermeiros, médicos e psicólogos) de um hospital de ensino, cujos dados foram submetidos à análise de conteúdo (Bardin, Minayo). Os resultados revelaram quatro categorias temáticas: 1) A compreensão dos profissionais sobre a autonomia do paciente, que, embora conceitualmente clara, enfrenta dificuldades de aplicação prática devido à falta de informação dos pacientes e ao foco curativista da medicina; 2) A experiência dos profissionais com pacientes em fase terminal e o envolvimento familiar, marcada por conflitos entre os desejos do paciente e da família, sendo frequente a prevalência da vontade familiar e o encaminhamento tardio aos cuidados paliativos; 3) A percepção da inserção precária das DAV no Brasil, decorrente da ausência de orientações, do amplo desconhecimento, da falta de regulamentação legal robusta e da insegurança profissional; e 4) O conhecimento dos profissionais sobre o Testamento Vital, que se mostrou incipiente e confuso, limitando sua efetiva utilização na prática clínica. Conclui-se que a implementação das DAV e do Testamento Vital requer uma profunda transformação na formação e na educação permanente dos profissionais de saúde, bem como a promoção do diálogo aberto e a consolidação de um marco legal claro, visando garantir a dignidade e o respeito à autonomia do paciente no final da vida.

Palavras-chave: Educação em Saúde. Profissionais de Saúde. Autonomia do Paciente. Diretivas Antecipadas de Vontade. Testamento Vital. Cuidados Paliativos.

RESUMEN

Los avances tecnológicos en la medicina, al prolongar la vida, han generado complejos dilemas éticos relacionados con la finitud, destacando la necesidad de garantizar la autonomía del paciente en el proceso de morir. Este capítulo, basado en una disertación de maestría, tiene como objetivo analizar la perspectiva del equipo multidisciplinario de salud sobre las Directivas Anticipadas de Voluntad (DAV) y el Testamento Vital (TV) en Brasil. La investigación cualitativa empleó entrevistas semiestructuradas con 21 profesionales (enfermeros, médicos y psicólogos) de un hospital universitario, cuyos datos fueron sometidos al análisis de contenido (Bardin, Minayo). Los resultados revelaron cuatro categorías temáticas: 1) La comprensión de los profesionales sobre la autonomía del paciente, que, aunque conceptualmente clara, enfrenta dificultades en su aplicación práctica debido a la falta de información de los pacientes y al enfoque curativista de la medicina; 2) La experiencia de los profesionales con pacientes en fase terminal y la participación familiar, marcada por conflictos entre los deseos del paciente y de la familia, prevaleciendo

frecuentemente la voluntad familiar y la derivación tardía a cuidados paliativos; 3) La percepción de la inserción precaria de las DAV en Brasil, debido a la falta de orientaciones, el amplio desconocimiento, la ausencia de una regulación legal sólida y la inseguridad profesional; y 4) El conocimiento de los profesionales sobre el Testamento Vital, que se mostró incipiente y confuso, limitando su uso efectivo en la práctica clínica. Se concluye que la implementación de las DAV y del Testamento Vital requiere una profunda transformación en la formación y educación continua de los profesionales de la salud, así como la promoción del diálogo abierto y la consolidación de un marco legal claro, con el objetivo de garantizar la dignidad y el respeto por la autonomía del paciente al final de la vida.

Palabras clave: Educación en Salud. Profesionales de la Salud. Autonomía del Paciente. Directivas Anticipadas de Voluntad. Testamento Vital. Cuidados Paliativos.

1 INTRODUCTION

Medical advancements, particularly in recent decades, have brought with them the promise of greater longevity and well-being. However, this evolution has also imposed new ethical and moral dilemmas on society and, especially, on healthcare professionals, particularly concerning the finitude of life (*AKDENIZ et al., 2021; LIN et al., 2023; KRUSE, 2024*). The technological capacity to prolong life, even in situations of unfavorable prognosis and intense suffering, has raised questions about the limits of medical intervention and the role of patient autonomy in the face of the inevitability of death (*SANTOS et al., 2024*).

In this complex scenario, Advance Directives (ADs) and Living Wills (LW) emerge as fundamental instruments to ensure that an individual's wishes and values are respected in the dying process (*NUNES & ANJOS, 2014; PIRÔPO et al., 2018; HOUSE et al., 2025*). These tools arise as a response to the need for patients, while still in full civil capacity and discernment, to express their preferences regarding treatments they accept or refuse for a time when they can no longer communicate or decide for themselves (*MABTUM & MARCHETTO, 2015*). The moral bindingness of these directives has been the subject of important ethical discussions, especially when there are conflicts of interest or values (*MONTANARI VERGALLO, 2023*).

In Brazil, Resolution No. 1.995/2012 of the Federal Council of Medicine (CFM) represents an important milestone by recognizing the right to patient autonomy and regulating ADs (*BRASIL, 2012*). This resolution allows any adult and conscious person to establish therapeutic limits for the final phase of their life, being an optional document, subject to modification or revocation at any time (*NUNES & ANJOS, 2014*). Despite this regulation, the effective implementation of ADs in clinical practice still faces numerous challenges, ranging from patients' and their families' lack of knowledge to insecurity and lack of training among healthcare professionals (*GOMES et al., 2018; MACEDO et al., 2023a; BAUMANN et al., 2023*).

The discussion about death, historically a taboo in many cultures, is increasingly shifting from the home to the hospital environment (*COSTA, 2024a*). In these settings, the absence of open and humanized dialogue about the finitude of life, combined with medicine focused on cure at all costs, often culminates in aggressive and futile treatments that prolong suffering without adding quality of life to the patient (*PAIS et al., 2019; LUNA-MEZA et al., 2021*). This context highlights the urgency of a paradigm shift, where palliative care is integrated early into treatment and where the multidisciplinary healthcare team is able to address finitude with empathy, respect, and knowledge (*PINTO et al., 2020; SUTHERLAND, 2019; MANGAL et al., 2024*).

This book chapter, based on Janaína Aparecida de Sales Floriano's dissertation, seeks to deepen the understanding of Advance Directives from the perspective of multidisciplinary healthcare professionals. It aims to analyze how these professionals deal with bioethical aspects related to the finitude of life, their knowledge of ADs and Living Wills, and the difficulties encountered in applying patient autonomy in the Brazilian context. The qualitative research interviewed nurses, physicians, and psychologists, seeking to unravel the meanings attributed to these concepts, as well as the barriers and facilitators for their implementation.

By recontextualizing and refining the dissertation's findings, this chapter aims to contribute to a broader and more accessible discussion on a topic of growing ethical and social relevance. The expectation is that it can offer subsidies to improve professional training, foster more humanized health policies, and empower patients and their families in making end-of-life decisions, promoting a dignified and respectful "good death" (*KIM & PARK, 2021*).

2 THEORETICAL FRAMEWORK: BIOETHICS AND END-OF-LIFE

The finitude of life is a universal and inevitable experience that, throughout history, has been approached by various cultures and belief systems (*FLORIANI, 2021; KRUSE, 2024*). However, in contemporary times, the way society deals with death has been profoundly impacted by technological and scientific advancements in healthcare. While modern medicine offers the hope of cures and prolonged life, it also imposes the need to reflect on the quality of life in its final stages and on the individual's right to decide about their own dying process (*SANTOS et al., 2024*).

In this context, Bioethics emerges as an essential interdisciplinary field of study, offering a conceptual and principled framework for the analysis and resolution of moral dilemmas that arise in the field of life and health sciences (*NOGARIO et al., 2020*). Among the fundamental bioethical principles, autonomy, beneficence, non-maleficence, and justice stand out, guiding clinical practice and the relationships among healthcare professionals, patients, and families.

2.1 BIOETHICAL PRINCIPLES IN END-OF-LIFE

The principle of autonomy grants the patient the right to decide about their own health and body, exercising their will freely and informedly (*MACEDO et al., 2023a; HOUSE et al., 2025*). This right is fully manifested in the ability to accept or refuse treatments, provided the patient is of legal age, lucid, and duly informed about the risks and benefits involved

(*BIFULCO & IOCHIDA, 2009*). In the context of end-of-life, autonomy becomes even more crucial, as it allows the individual to express their preferences on how they wish to be cared for when they can no longer do so (*MONTANARI VERGALLO, 2023*). Valuing patient autonomy is one of the pillars of modern medicine and is the foundation of Advance Directives.

The principle of beneficence imposes on healthcare professionals the obligation to act for the benefit of the patient, seeking their well-being and promoting their health. However, at the end of life, "benefit" may not be the prolongation of life at all costs, but rather the alleviation of suffering and the maintenance of dignity (*PINTO et al., 2020*). Beneficence must be weighed against autonomy, ensuring that medical actions are aligned with the patient's values and wishes.

Non-maleficence is the duty not to cause harm to the patient. At the end of life, this means avoiding futile, invasive, or painful treatments that do not offer prospects of cure or significant improvement, merely prolonging suffering (*NOGARIO et al., 2020*). Dysthanasia, a concept that will be addressed later, is a classic example of a violation of this principle.

Finally, the principle of justice refers to the equitable allocation of health resources and the guarantee that all patients are treated with equality and dignity, regardless of their social, economic, or health status (*NOGARIO et al., 2020*). In the context of finitude, justice implies ensuring that everyone has access to quality palliative care and the opportunity to exercise their autonomy.

2.2 ESSENTIAL CONCEPTS ON END-OF-LIFE

To understand the discussions surrounding Advance Directives, it is essential to distinguish some key concepts related to death and the dying process:

2.2.1 Euthanasia, Dysthanasia, and Orthothanasia

Euthanasia: Derived from Greek "eu" (good) and "thanatos" (death), meaning "good death" or "death without suffering." It refers to the anticipation of death of a patient with an incurable disease and intense suffering, through a deliberate action aimed at ending their life (*FRANÇA, 2019, p. 564*). In Brazil, euthanasia is prohibited and considered a crime (Article 121 of the Penal Code, 1940).

Dysthanasia: From Greek "dys" (bad, anomalous) and "thanatos" (death), describes the artificial prolongation of life in situations of intense suffering and without prospect of cure, through futile or disproportionate treatments (*SÁ, 2015, p. 87*). It is the so-called "therapeutic obstinacy," which goes against the Code of Medical Ethics (*BRASIL, 2018*), which

recommends that physicians offer palliative care without undertaking useless or obstinate actions. Dysthanasia violates patient dignity and the principle of non-maleficence (*TOMINAGA et al., 2024*).

Orthothanasia: From Greek "orthós" (right, normal, correct) and "thánatos" (death), meaning "death at the right time" or "dignified death." It involves allowing death to occur naturally, without anticipating it (euthanasia) or artificially prolonging it (dysthanasia), focusing on the alleviation of suffering and the maintenance of quality of life (*GODIM, 2004*). CFM Resolution No. 1.805/2006 (*BRASIL, 2006*) allows physicians to limit or suspend procedures and treatments that prolong the life of terminally ill patients with severe and incurable diseases, respecting their autonomy.

2.2.2 Mistanasia and Kalothanasia

Mistanasia: Derived from Greek "mys" (unfortunate) and "thanatos" (death), meaning "unfortunate death," premature and preventable. It refers to deaths resulting from a lack of access to minimum conditions for a dignified life, such as basic sanitation, food, health, and security, often perpetuated by negligence or inefficiency of public policies (*FERREIRA, 2019*). It is a concept that expands the discussion about death beyond the individual clinical context.

Kalothanasia: From Greek "kalós" (good, beautiful) and "thanatos" (death), meaning "beautiful death" or "good death." This concept goes beyond orthothanasia, which focuses on death at the right time, incorporating cultural, religious, and personal aspects that make the dying process meaningful for the patient and their families. It involves respect for the individual's life history, their last wishes, the presence of loved ones, and farewell rituals, seeking a transformative meaning for illness and the dying process (*FLORIANI, 2021*). Kalothanasia emphasizes the dignity and sacredness of the final moment of life, integrating the physical, emotional, spiritual, and social dimensions of the patient.

2.3 ADVANCE DIRECTIVES (ADS) AND LIVING WILL (LW)

Advance Directives (ADs) are documents in which a person, in full exercise of their mental capacity, declares their preferences regarding healthcare they wish to receive or refuse in the future, should they find themselves in a condition that prevents them from autonomously expressing their will (*BRASIL, 2012; HOUSE et al., 2025*). These directives are particularly relevant for patients with terminal, incurable diseases or with irreversible clinical conditions (*MABTUM & MARCHETTO, 2015*). CFM Resolution No. 1.995/2012 establishes that the patient's directives will prevail over any other non-medical opinion,

including family wishes, guaranteeing the primacy of individual autonomy (*MONTANARI VERGALLO, 2023*).

A Living Will (LW) is a type of Advance Directive, a more specific document with legal validity, in which the individual records their choices about the treatments they wish or do not wish to receive in situations of serious illness or irreversible damage, when incapacitated to decide for themselves (*LOMBARDI & SANTOS, 2019*). Historically, the case of Nancy Cruzan in the United States (1980s) was emblematic for the discussion about the right to a dignified death and the importance of a written document that attested to the patient's wishes (*UNITED STATES SUPREME COURT, 1990; DADALTO, 2018*). The living will, unlike a common will, does not refer to the distribution of material goods, but rather to decisions about one's own body, health, and dignity at the end of life (*BREDAS & NINGELISKI, 2024*).

The implementation of ADs and LWs seeks to ensure human dignity, a fundamental constitutional principle (*BRASIL, 1988*), and the right to self-determination. However, practice still faces significant barriers, such as a lack of knowledge among professionals and the population, the absence of more robust legal regulation in Brazil, and ethical conflicts that arise between the patient's will, the family's wishes, and the healthcare team (*SCHINISKI, 2023; CETOLIN et al., 2024; MACEDO et al., 2023a; BAUMANN et al., 2023*). The effectiveness of ADs can be complex in specific conditions, such as in patients with dementia, where decisions about feeding and nutrition raise new debates about the limits of autonomy and the interpretation of directives (*SHELTON & GEPPERT, 2024*). Similarly, in neurodegenerative diseases like amyotrophic lateral sclerosis (ALS), ADs prove to be fundamental tools for care planning, requiring professionals to be well-prepared for this discussion (*MANGAL et al., 2024*).

The discussion about the end of life is not limited to the patient, but also involves their family and the multidisciplinary healthcare team. A collaborative approach, including physicians, psychologists, nurses, social workers, and other professionals, is fundamental to offer comprehensive care, alleviate suffering, and promote understanding of the illness and what can still be experienced (*CRUZ et al., 2021; EBSERH, 2023*). The training and capacity-building of these professionals are essential so that they can deal with the complexity of the topic, initiate conversations about finitude in a humanized way, and ensure that patient autonomy is effectively respected (*SUTHERLAND, 2019; BAUMANN et al., 2023; MÜLLER et al., 2024*).

3 METHODOLOGY

This chapter is based on descriptive research, with a qualitative approach and a convenience sample, whose main objective was to identify the meanings attributed to advance directives by multidisciplinary healthcare professionals. The methodology employed aims to deepen the understanding of how health professionals experience and interpret the bioethical aspects related to the finitude of life and knowledge about ADs in Brazil (*FLORIANO, 2025*).

3.1 PARTICIPANTS AND SELECTION CRITERIA

Twenty-one multidisciplinary healthcare professionals participated in the research: seven nurses, seven physicians, and seven psychologists. Participant selection occurred through convenience sampling at a high-complexity teaching hospital in São José do Rio Preto/SP.

Inclusion criteria were: being a healthcare professional (nurse, physician, or psychologist) and having worked for at least one year with end-of-life patients in sectors such as palliative care, hemodialysis, oncology, and intensive care unit (ICU). Exclusion criteria were: being a technician, trainee professional, or resident physician (*FLORIANO, 2025*).

3.2 DATA COLLECTION PROCEDURE

Professionals were approached at their respective workplaces, after authorization from their superiors and according to their availability. After receiving detailed explanations about the study and agreeing to participate, they signed the Free and Informed Consent Form (FICF), in accordance with Resolution No. 510/2016 of the National Health Council (*BRASIL, 2016*), ensuring research ethics.

Participants' demographic information was collected through a sociodemographic questionnaire. Subsequently, semi-structured interviews were conducted in person with the researcher, lasting an average of 20 to 30 minutes. The interviews were guided by the following guiding questions:

- What do you understand by patient autonomy?
- I would like you to describe your experience with terminally ill patients and family involvement in these cases.
- How do you perceive the insertion of Advance Directives in Brazil (ADs – Resolution No. 1.995, of 2012, of the Federal Council of Medicine)?
- Have you ever heard of a Living Will? If so, could you explain it in your own words?

Participants' responses were audio-recorded and subsequently transcribed in full by the researcher, ensuring the fidelity of the reports (*FLORIANO, 2025*).

3.3 DATA ANALYSIS: CONTENT ANALYSIS

Qualitative data analysis was performed using Content Analysis, a technique that allows for the systematic and objective description of message content, as well as the inference of knowledge about the conditions of production and reception of these messages (*BARDIN, 2011*). This method is widely recognized in qualitative research for its ability to uncover hidden meanings and patterns in textual data, being particularly suitable for understanding subjective perceptions and experiences, as addressed in this study (*MINAYO, 2017*).

The Content Analysis process followed the steps proposed by Bardin (*2011*) and reinforced by Minayo (*2017*):

3.3.1 Pre-analysis

This initial stage involved organizing the collected material. The transcribed interviews were read and re-read exhaustively, allowing the researcher to become deeply familiar with the data. It was a "floating" phase, where the first impressions were sought, recurrent themes were identified, and a coherent analysis corpus was built. The corpus was constituted and an analysis script with the initial indicators was prepared, ensuring the exhaustiveness, representativeness, homogeneity, and relevance of the documents (*BARDIN, 2011*).

3.3.2 Material Exploration

In this phase, the textual material was systematically explored. Procedures for cutting, coding, enumeration, and classification were applied. Recording units (relevant text segments) were identified and coded, i.e., transformed into meaning units. Coding aimed to categorize information based on theoretical and empirical criteria. The objective was to group participants' "speeches" into meaningful sets that answered the research questions. This process involved identifying central themes and creating provisional categories that emerged from the data (*MINAYO, 2017*).

3.3.3 Results Treatment, Inference, and Interpretation

In this stage, the previously identified categories were deepened and refined. Coded data were organized, and the frequencies and relationships between categories were examined. The thematic categories were established based on the recurrence and relevance

of the themes addressed by the professionals. The analysis allowed the reports to be grouped into four categories of meanings, representing the main dimensions of participants' perception of Advance Directives.

Inference and interpretation, the moment of greatest theoretical elaboration, involved linking empirical results with the theoretical framework. The aim was to go beyond the description of data, seeking to establish relationships, infer broader meanings, and understand the implications of the findings for clinical practice and public health policies. Interpretation was enriched by dialogue with existing literature on bioethics, autonomy, palliative care, and legal aspects of ADs, as detailed in the Theoretical Framework section. This process allowed for building a more comprehensive and critical understanding of the studied phenomenon (*BARDIN, 2011; MINAYO, 2017*).

3.4 ETHICAL ASPECTS

The study was approved by the Research Ethics Committee (CAEE 74812323.4.0000.5415), opinion no. 6.499.813, on December 11, 2023 (*FLORIANO, 2025*). To ensure participants' anonymity and confidentiality, their identities were preserved. In the presented reports, participants were identified by the letter “P” (participant), followed by symbolic numbers that do not represent the order of "speeches" or professional category, making identity traceability impossible.

4 PARTICIPANTS' CHARACTERIZATION

The research interviewed 21 multidisciplinary healthcare professionals. Data collection occurred between February 28, 2024, and June 10, 2024. Table 1 presents the sociodemographic characterization of the participants.

Table 1

Participants' Characterization (n=21)

Characteristic	n	Frequency (%)
Sex		
Female	17	80.95
Male	4	19.05
Experience Time		
Between 1 and 5 years	6	28.57
Between 6 and 10 years	7	33.33

Characteristic	n	Frequency (%)
Between 11 and 20 years	5	23.81
Above 21 years	3	14.29
Education Level		
Master's degree	3	14.29
Doctorate degree	2	9.52
Undergraduate degree	1	4.76
Postgraduate lato sensu	15	71.43
Age (mean ± standard deviation)	37.7 (±8.5)	-
Profession		
Nurse	7	33.33
Physician	7	33.33
Psychologist	7	33.33
Religion		
Yes	20	95.24
No	1	4.76

Source: Floriano (2025)

The majority of participants (80.95%) were female, with a mean age of 37.7 years (±8.5). The sample was equally divided among nurses, physicians, and psychologists (33.33% each). The predominant education level was postgraduate *lato sensu* (71.43%), followed by master's (14.29%) and doctorate (9.52%). Only one participant had only an undergraduate degree. The vast majority (95.24%) declared having a religion. Professional experience time varied, with most (33.33%) having between 6 and 10 years of experience (*FLORIANO, 2025*).

5 RESULTS AND DISCUSSION

From the content analysis of the interviews, following the steps described by Bardin (*2011*) and Minayo (*2017*), four main thematic categories emerged, representing the meanings attributed by healthcare professionals to Advance Directives and related topics. These categories reveal the complexity of the end-of-life scenario in the hospital environment and professionals' perceptions of patient autonomy.

5.1 CATEGORY 1: HEALTHCARE PROFESSIONALS' UNDERSTANDING OF PATIENT AUTONOMY, ACCORDING TO RESOLUTION NO. 1.995/2012 OF THE FEDERAL COUNCIL OF MEDICINE

The results indicate that the interviewed healthcare professionals understand the conceptual meaning of patient autonomy, linking it to the capacity for informed decision-making. In Brazil, this understanding is formally supported by CFM Resolution No. 1.995/2012 and, more broadly, by the Code of Medical Ethics (*BRASIL, 2012; BRASIL, 2018*). However, despite this conceptual clarity, participants recognize various difficulties in its effective application in clinical practice. Autonomy is seen as the patient's right to choose their treatment, provided they are fully conscious and informed about their condition and the implications of their decisions (*MACEDO et al., 2023a; HOUSE et al., 2025*).

For participants, autonomy manifests when the patient has full knowledge of their pathology, therapeutic options, and the risks and benefits of each choice. This understanding is fundamental for the decision to be truly autonomous and not merely passive acceptance.

- "From a medical point of view (...) I understand that they are aware of their pathology, prior to hospitalization, and that they have the power to decide what type of treatment they want to undergo over time and their therapy (P1)."
- "Autonomy is when the patient has full knowledge... of the benefits, the risks of their decisions. So, autonomy is the patient's will, provided they have knowledge of each procedure, each choice, its risks and benefits (P4)."

Despite this conceptual clarity, professionals point out that patients' lack of knowledge on the subject, difficulty in understanding their diagnosis and treatment options, as well as adherence to values and beliefs, can hinder the full exercise of autonomy (*MACEDO et al., 2023a*). It is not enough for the professional to understand the concept; it is imperative that the patient and their family also understand it for effective application (*SEREY et al., 2022*). The moral relevance of Advance Directives is a central issue, and their binding nature must be respected to preserve patient dignity (*MONTANARI VERGALLO, 2023*).

The absence of advance planning is a factor that frequently leads to aggressive and unnecessary treatments, contrary to the patient's last wishes (*KRUSE, 2024*). This highlights the need for end-of-life discussions to occur early, involving the family and considering the patient's culture (*THOMAS et al., 2020*). There is, therefore, an urgency to continuously train professionals to ensure the fulfillment of individuals' expressed wishes, especially in surgical and palliative care settings (*SHAPIRO & SINGER, 2019; FONTES et al., 2020; MANGAL et al., 2024*).

Ethical dilemmas intensify when patient autonomy conflicts with medicine centered on cure at all costs, a paternalistic view that often fails to prepare future physicians to deal with the finitude of life (*COSTA et al., 2023*). The Supreme Federal Court's (STF) decision on Jehovah's Witnesses' right to refuse blood transfusions exemplifies the primacy of the principle of autonomy over beneficence in certain contexts, demonstrating the strength of respecting individual will in cases of conflict (*BRASIL, 2024*).

5.2 CATEGORY 2: HEALTHCARE PROFESSIONALS' EXPERIENCE WITH TERMINALLY ILL PATIENTS AND FAMILY INVOLVEMENT

This category revealed that professionals' experience with terminally ill patients is marked by a constant dilemma between the patient's will and family interference, a common finding in reviews on the subject (*MACEDO et al., 2023a*). Frequently, family will ends up prevailing, generating conflicts and compromising patient autonomy, especially in vulnerable situations.

Reports indicate a significant difficulty for families in accepting finitude and respecting patient decisions, often opting for life prolongation at all costs, even if it implies additional suffering, a reality also observed in intensive care environments (*BAUMANN et al., 2023*).

- "There are patients who understand the situation. They don't want to undergo treatment, but the family determines that the patient will indeed undergo treatment... they want to prolong the patient's life. And this harms their quality of life (P8)."
- "In fact, what I see happening is precisely this difficulty; the patient's desire is often different from the family's, and the patient's and family's desire is different from what the healthcare team wants. So, yes, there are many conflicts (P15)."

This family imposition, coupled with professionals' difficulty in addressing terminality, leads to patients being referred to palliative care only when they are already in an advanced dying process, unable to express their wishes (*KRUSE, 2024*). This highlights the urgency of advance planning and more effective communication. The Federal Constitution of 1988 (*BRASIL, 1988*) and the Civil Code (*BRASIL, 2002*) protect human dignity and private autonomy, making the imposition of unwanted treatments a violation of these rights (*DADALTO, 2014; BREDA & NINGELISKI, 2024*). The moral duty to respect patient directives, even when at odds with the family, has been emphasized in bioethics (*MONTANARI VERGALLO, 2023*).

A lack of early dialogue about end-of-life, fear of death, and anticipatory grief in the family are factors contributing to these conflicts. Professionals also experience suffering when faced with family or even other team members' refusal to accept patient decisions

(*LUNA-MEZA et al., 2021*). A lack of team preparedness to deal with finitude, the culture of cure, and the absence of clear protocols to mediate these conflicts are significant barriers (*PINTOS et al., 2020; BAUMANN et al., 2023*). In specific contexts, such as patients with dementia, the interpretation of ADs related to feeding and nutrition can be particularly complex, generating additional dilemmas for the team and family (*SHELTON & GEPPERT, 2024*). The need for clear guidelines on ADs for patients with mental disorders is also an emerging challenge, requiring specific recommendations for practice (*MÜLLER et al., 2024*).

The role of the multidisciplinary team is crucial for mediating these conflicts and ensuring that the patient's will is prioritized, but this requires specific training and institutional support (*MINAME et al., 2023*). Effective communication, active listening, and the ability to adapt to the patient's and family's values and beliefs are essential skills to promote a "good death" (*CHENG et al., 2019; SOMMER et al., 2021*).

5.3 CATEGORY 3: HEALTHCARE PROFESSIONALS' PERCEPTION OF ADVANCE DIRECTIVES' RELEVANCE IN CLINICAL PRACTICE

Professionals express a perception that the insertion of Advance Directives in Brazil is still "precarious" and "in its infancy," a view echoed in studies evaluating the population's and professionals' perception and knowledge of the topic (*MACEDO et al., 2023a; MACEDO et al., 2024*). There is an acknowledgment of the importance of ADs, but also a strong sense of lack of guidance, widespread unawareness, and insecurity in application, both by professionals and by patients and families.

The lack of legal regulation is pointed out as one of the main causes of insecurity, despite the existence of CFM Resolution No. 1.995/2012. Many professionals fear the judicialization of conduct.

- "Oh my! I think it's very precarious, very precarious. The treatment that cares most about directives is palliative care; oncology also has some participation, but most other specialties... they look at the medical side of curative treatment and don't pay much attention to patient autonomy. There's a great lack of guidance (P5)."
- "And the lack of legal regulation ends up influencing the non-compliance with advance directives a lot (P7)."

There is a perception that the healthcare system is not prepared to integrate ADs, both in terms of record-keeping in medical charts and workflow. Experience in intensive care units, for example, reveals that translating patients' advance directives into practice is still a significant challenge, with much progress to be made (*BAUMANN et al., 2023*). The medical

culture, still very focused on cure, also hinders the acceptance and implementation of these directives (*GOMES et al., 2018*).

- "If someone arrives with their birth plan or any other advance directive, the health service is not ready to take it and say 'I'm going to attach it to the medical chart.' Where do I put this?... I don't have a tab to insert it (P6)."

The scarcity of scientific production and the lack of consensus on ADs in Brazil contribute to the lack of knowledge and difficulty in dissemination (*HASSEGAWA et al., 2019*). Studies on the effective use of ADs in specific populations, such as veterans in the USA, show that, while awareness may exist, practical utilization can be inconsistent, underlining the need for more effective policies and education (*TUNG & YEH, 2023*). This contrasts with countries where the population has more favorable attitudes and greater knowledge about ADs (*MACEDO et al., 2024*).

It is evident that undergraduate training and continuing education are essential to change this scenario, introducing the debate on patient rights and bioethics early on (*CETOLIN et 2024; MÜLLER et al., 2024*).

Despite the challenges, there is a consensus among professionals about the importance of discussing directives and the need for legislation that offers legal certainty for their implementation. Advance care planning is seen as an essential process to strengthen autonomy and promote open communication, resulting in better quality of life for the patient and less suffering for all involved (*SEDINI et al., 2022; SOMMER et al., 2021*).

5.4 CATEGORY 4: HEALTHCARE PROFESSIONALS' KNOWLEDGE OF LIVING WILLS

This category reveals significant unawareness and conceptual confusion between Advance Directives and Living Wills among many professionals. While some demonstrate some familiarity with the Living Will, others have never heard the term or confuse it with other legal or material issues, a reflection of what systematic reviews have pointed out about the general level of knowledge regarding ADs (*MACEDO et al., 2023a*).

The lack of conceptual clarity compromises the correct application of the Living Will in clinical practice and limits professionals' ability to guide patients and families. The Living Will is, in fact, a specific form of Advance Directive, and its understanding is fundamental for the healthcare team's actions (*HOUSE et al., 2025*).

- "I have never heard of this term (P6)."
- "I think I don't have the technical training to think about a living will as a whole; I still think I would need to study a lot to be able to define it. Today I can't (P7)."

Those who demonstrated some knowledge generally associate it with a document that expresses the patient's end-of-life wishes, covering non-material aspects, but related to dignity and the way one wishes to die.

- "That does not concern material issues, but concerns their own dignity, right? Which are all the things that are pertinent to sustain and structure that person's dignity (P9)."
- "Yes. I also understand it as a directive. As a record of this advance directive so that it's not just in words, but recorded while the patient still has life and is... able to respond, to be conscious, so that when they are no longer here... (P15)."

The confusion between ADs and LWs is a critical point, as the Living Will is a specific form of Advance Directive, more focused on formal, and sometimes legal, documents. The case of Nancy Cruzan, which prompted the development of Living Wills in the USA, illustrates the importance of having these wishes formalized (*UNITED STATES SUPREME COURT, 1990; DADALTO, 2018*). In progressive diseases like Amyotrophic Lateral Sclerosis (ALS), ADs are essential instruments that can be facilitated by specific interventions, reinforcing the need for healthcare professionals to fully understand these concepts (*MANGAL et al., 2024*).

Continuing education in bioethics and the inclusion of these topics in professional training are essential to address this knowledge gap (*MINAME et al., 2023*). A lack of information and communication difficulties can compromise individual autonomy, leading to their wishes not being respected (*FERRARIO et al., 2023*). Training professionals to deal with finitude and offer adequate palliative care is fundamental to ensuring a dignified and respectful death (*TOMINAGA et al., 2024; MÜLLER et al., 2024*).

In summary, the results show that, although healthcare professionals understand the importance of patient autonomy, knowledge about ADs and, in particular, Living Wills is still incipient and confused. Cultural barriers, family interference, lack of regulation, and professional insecurity prevent the full implementation of these instruments, reinforcing the need for a profound transformation in the approach to end-of-life in Brazilian medicine (*PAIS et al., 2019*).

6 STUDY LIMITATIONS

The present research, although offering valuable insights into the multidisciplinary healthcare team's perspective on Advance Directives, has some limitations intrinsic to its nature and methodological design. It is important to acknowledge them to contextualize the findings and inspire future investigations.

Firstly, the research used a convenience sample consisting of 21 professionals from a single high-complexity teaching hospital in São José do Rio Preto/SP. Although this approach

allowed for an in-depth understanding of this specific group's perceptions, the results may not be generalizable to other hospital contexts, regions of Brazil, or different types of healthcare institutions (*BARDIN, 2011*). Hospitals with different organizational cultures, levels of investment in continuing education, or patient profiles may present distinct realities, as observed in studies comparing population attitudes in different countries (*MACEDO et al., 2024*).

Secondly, the qualitative approach, by its nature, does not seek statistical generalization, but rather a deep understanding of phenomena and the richness of meanings attributed by participants (*MINAYO, 2017*). Although content analysis allowed for the emergence of robust and illustrative categories, data interpretation is sensitive to the researcher's perspective.

Thirdly, the self-reported nature of the interviews may have influenced participants' responses. Although anonymity was guaranteed, professionals may have expressed perceptions they consider socially desirable or that minimize their own knowledge gaps and insecurities, especially on such a sensitive and complex topic as end-of-life and bioethics (*MACEDO et al., 2023a*).

Fourthly, the research focused on the perspective of healthcare professionals, leaving out the voices of patients and their families, who are intrinsic and equally important parties in the decision-making process regarding ADs. Including these perspectives could significantly enrich the understanding of the dilemmas and challenges involved in implementing directives, including the complexities in cases such as dementia or mental disorders (*SHELTON & GEPPERT, 2024; MÜLLER et al., 2024*).

Fifthly, the absence of specific and comprehensive legislation on ADs in Brazil (beyond the CFM Resolution) is a contextual limitation that permeates the study. The lack of legal certainty, frequently mentioned by participants, reflects a gap that transcends the sphere of individual research, impacting practice at a national level (*SCHINISKI, 2023; HOUSE et al., 2025*).

Finally, the data collection period, although recent (2024), reflects a specific moment in the evolution of discussions about bioethics in the country. The constant evolution of medicine, legislation, and public awareness may generate new perceptions and challenges not captured by this study.

Despite these limitations, the findings provide a solid basis for understanding the barriers and facilitators in implementing Advance Directives in Brazil, from the viewpoint of those who deal directly with the finitude of life, opening avenues for future investigations and interventions.

7 RECOMMENDATIONS FOR FUTURE RESEARCH

Based on the gaps identified in the present research and the reflections generated by the results, several avenues for future investigations emerge as fundamental to deepen knowledge and promote the effectiveness of Advance Directives in Brazil. The following recommendations aim to improve understanding of the topic and support the formulation of public health policies and more humanized practices in end-of-life care.

7.1 COMPREHENSIVE AND MULTICENTRIC STUDIES

The realization of large-scale, multicentric research is recommended, involving healthcare professionals from different geographical regions, types of hospitals (public and private, university and non-university), and levels of complexity. This approach would allow for identifying variations in perceptions and practices, offering a more representative overview of the Brazilian reality and expanding the generality of the findings (*MACEDO et al., 2023a; KRUSE, 2024*). Comparing the Brazilian situation with that of other countries that have advanced in the implementation of ADs, as evidenced in studies on population attitudes (*MACEDO et al., 2024*) or effective use in different groups (*TUNG & YEH, 2023*), can provide valuable insights.

7.2 PATIENT AND FAMILY PERSPECTIVES

It is fundamental that future research explores the perspective of patients and their families on Advance Directives. Qualitative studies investigating their experiences, knowledge, values, beliefs, and challenges in drafting and communicating ADs would be extremely valuable (*CHENG et al., 2019*). Understanding their desires and difficulties is essential to develop communication and support strategies that are truly patient-centered, including the complexities in scenarios such as dementia or mental disorders, where expressed will may have unique implications (*SHELTON & GEPPERT, 2024; MÜLLER et al., 2024*).

7.3 IMPACT OF ACADEMIC TRAINING AND CONTINUING EDUCATION

Investigations can focus on the impact of including disciplines on bioethics, palliative care, and ADs in the curriculum of health undergraduate courses (Medicine, Nursing, Psychology, among others). Furthermore, it would be relevant to evaluate the effectiveness of continuing education and training programs for active professionals, measuring not only increased knowledge but also changes in attitudes and the incorporation of these practices into daily clinical routines (*SUTHERLAND, 2019; BAUMANN et al., 2023*). Training should

prepare professionals for discussing and drafting ADs in various clinical conditions, including complex neurodegenerative diseases (*MANGAL et al., 2024*).

7.4 INSTITUTIONAL AND CULTURAL BARRIERS

New research could analyze the institutional barriers that hinder the implementation of ADs, such as a lack of clear protocols, the absence of electronic health record systems that integrate these directives, and cultural resistance within healthcare institutions and among team members (*BAUMANN et al., 2023*). Investigating successful models in other countries and their adaptability to the Brazilian context would be fruitful, considering how ADs are implemented and recognized in different legal and cultural systems (*MAFFONI et al., 2020; SEDINI et al., 2022; HOUSE et al., 2025*).

7.5 LEGAL AND LEGISLATIVE ASPECTS

Given that the lack of legal regulation was pointed out as a source of insecurity, legal and sociological studies could focus on the need and format of more robust legislation to support ADs in Brazil. It would be relevant to analyze the impact of specific legal frameworks and the perception of their contribution to professional safety and respect for patient autonomy (*SCHINISKI, 2023; MONTANARI VERGALLO, 2023*).

7.6 DEVELOPMENT OF SUPPORT TOOLS

Applied research could concentrate on the development and validation of support tools for healthcare professionals, patients, and families in drafting ADs and Living Wills. This would include practical guides, educational materials, document templates, and digital platforms that facilitate the recording and access to directives (*MCMAHAN et al., 2021*).

7.7 CASE STUDIES AND DETAILED CLINICAL ANALYSES

The conduct of case studies or in-depth clinical analyses of real situations where ADs were (or were not) applied could provide valuable insights into practical challenges, ethical dilemmas faced, and outcomes for patients, families, and teams. This includes the analysis of complex cases where the interpretation of ADs becomes ambiguous or challenging (*SHELTON & GEPPERT, 2024*).

By addressing these recommendations, future research can build a more complete and applicable body of knowledge, effectively contributing to patient autonomy being fully respected in the end-of-life context, and to healthcare professionals being more prepared and secure to deal with this essential dimension of human care.

8 CONCLUSION

This investigation, based on Janaína Aparecida de Sales Floriano's master's dissertation and adapted for this book chapter, provided an in-depth analysis of the multidisciplinary healthcare team's perspective on Advance Directives (ADs) and Living Wills in the Brazilian context. The results confirm that the complexity of the finitude of life, coupled with technological advancements in medicine, imposes significant ethical dilemmas that demand continuous reflection and improvement of healthcare practices (*KRUSE, 2024*).

In summary, healthcare professionals understand patient autonomy as the fundamental right to make informed decisions about their treatment and the dying process. However, the effective application of this principle is often hindered by patients' and families' lack of knowledge, cultural resistance to discussing death, and conflicts that arise between patient wishes, family expectations, and healthcare team guidelines (*MACEDO et al., 2023a; BAUMANN et al., 2023*). It was noted that, in most cases, family will tends to prevail, disrespecting individual autonomy and prolonging futile treatments, leading to unnecessary suffering, in clear opposition to the morally binding nature of ADs (*MONTANARI VERGALLO, 2023*).

The insertion of Advance Directives in Brazil, despite the existence of CFM Resolution No. 1.995/2012, is perceived as "precarious" and "in its infancy." There is a clear lack of guidance and knowledge on the subject among professionals, patients, and families (*MACEDO et al., 2024; TUNG & YEH, 2023*). The absence of more robust legal regulation and the fear of judicialization of conduct generate insecurity among professionals, contributing to the underutilization of these instruments (*SCHINISKI, 2023; HOUSE et al., 2025*). Furthermore, conceptual confusion between ADs and Living Wills was evidenced, which prevents their correct application in clinical practice and the realization of the patient's last wishes. Complexity increases in specific situations, such as patients with dementia or mental disorders, where the interpretation of directives requires additional considerations (*SHELTON & GEPPERT, 2024; MÜLLER et al., 2024*).

Given these findings, it becomes imperative that health education undergoes a profound transformation. The inclusion and strengthening of bioethics disciplines, palliative care, and end-of-life legislation in curricula, as well as continuing education programs for active professionals, are essential. This training should aim not only to increase technical knowledge but also to develop interpersonal communication skills, empathy, and the ability to initiate and conduct sensitive dialogues about death with patients and their families (*SUTHERLAND, 2019; BAUMANN et al., 2023; MANGAL et al., 2024*).

The promotion of open and transparent dialogue among all involved, patients, families, and healthcare teams, is fundamental to building advance care planning that respects the individual's values, beliefs, and wishes, ensuring them a dignified death with less suffering. This implies overcoming the taboo surrounding death and facing finitude as a natural part of life, integrating palliative care early into treatment.

Ultimately, this chapter reiterates the need for a more humanized and individualized approach to end-of-life care, supported by solid bioethical principles and a legal framework that offers security and clear guidelines. Only then will it be possible to ensure that patient autonomy is fully respected, and that the dying process is experienced with the dignity that every human being deserves.

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