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Advance directives and palliative care: Brazilian perception

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Abstract

Advance directives are considered a fundamental component of health care planning, a resource commonly used by palliative care teams. Given the importance of the care network for patients with incurable and life-threatening diseases, this study aims to investigate the understanding that health professionals, patients, and caregivers have of the subject, in addition to understanding how the subject is conceptualized, identifying convergences and divergences in the discourses and how these notions can influence the quality of care. We opted for an integrative review of the scientific literature, in which eight articles were selected and analyzed. Priority was given to dividing the discussion into three descriptive topics and analyzing them critically. Thus, the need to continue debating this topic is evident in order to ensure the development of patient-centered behaviors that take into account their socioeconomic conditions and personal values.

Keywords: Advance directives. Palliative care. Terminal care. Medical ethics.

Resumo

Diretivas antecipadas de vontade e cuidados paliativos: percepção brasileira

As diretivas antecipadas de vontade são consideradas um componente fundamental do planejamento de cuidados de saúde, recurso comumente empregado por equipes de cuidados paliativos. Dada a importância da rede de cuidado para o paciente com doença incurável e que ameaça sua vida, este estudo tem o objetivo investigar a compreensão que profissionais da saúde, pacientes e cuidadores têm da temática, além de apreender como o tema é conceituado, identificar convergências e divergências nos discursos e discutir como essas noções podem influenciar na qualidade do cuidado. Optou-se pela revisão integrativa da literatura científica, em que foram selecionados e analisados oito artigos. Com isso, priorizou-se dividir a discussão em três tópicos descritivos e analisá-los criticamente. Desse modo, fica evidente a necessidade de continuar a debater essa temática a fim de garantir o desenvolvimento de condutas centradas no paciente, que contemplem suas condições socioeconômicas e seus valores pessoais.

Palavras-chave: Diretivas antecipadas. Cuidados paliativos. Cuidados de fim de vida. Ética médica.

Resumen

Voluntades anticipadas y cuidados paliativos: percepción brasileña

Las directivas anticipadas se consideran fundamentales en la planificación de la atención de la salud, un recurso comúnmente utilizado por los equipos de cuidados paliativos. Dada la importancia de la red de atención para pacientes con enfermedad incurable y potencialmente mortal, este estudio pretende investigar la comprensión que los profesionales de salud, pacientes y cuidadores tienen sobre el tema, además de comprender cómo se conceptualiza el tema, identificar convergencias y divergencias en los discursos y discutir cómo estas nociones pueden influir en la calidad de la atención. Se realizó una revisión integradora de la literatura científica, en la que se seleccionaron y analizaron ocho artículos. Así, se dio prioridad a dividir la discusión en tres temas descriptivos y analizarlos críticamente. Se evidencia la necesidad de seguir debatiendo este tema para garantizar el desarrollo de comportamientos centrados en el paciente, que incluyan sus condiciones socioeconómicas y valores personales.

Palabras clave: Directivas Anticipadas. Cuidados paliativos. Cuidados al final de la vida. Ética Médica.

The authors declare no conflict of interest.

In Brazil, advance directives (ADs) are widely seen as another name for a living will (LW), a document that allows a person to express their preferences and wishes regarding the medical care they wish to receive if they become incapable of making autonomous decisions¹. Historically, the emergence of advance directives dates back several decades and reflects growing concerns about patient rights and the advancement of modern medicine¹⁻³.

The idea of encouraging people to express their wishes regarding future medical care gained traction in the United States in the 1960s, particularly after a series of court cases involving patients in a persistent vegetative state^{1,3}. Thus, ADs began to be developed to allow individuals to express their healthcare preferences in the event of future disabilities¹⁻³.

In 1991, the United States approved the Patient Self-Determination Act^{1,3}. It required healthcare institutions that received federal funding to inform patients of their right to make advance will directives. This law was an important milestone in promoting the use of these documents and mainly in promoting the discussion about terminal illness with quality of life¹⁻³.

Since then, many other countries worldwide have also adopted similar legislation to ensure that people have the right to express their wishes regarding future medical care². In Brazil, while there is still no specific legislation that addresses the rights of terminally ill people, some resolutions from the Federal Council of Medicine (CFM) can help in understanding the topic.

CFM Resolution 1,805/2006 determines that the physician is allowed to *limit or suspend procedures and treatments that prolong the life of a sick person in a terminal phase or with a serious and incurable illness, respecting the wishes of the person and their legal representative*⁴. Art. 41 of CFM Resolution 1,931/2009 states that in cases of *incurable and terminal illness, the physician must offer all available palliative care without undertaking useless or obstinate diagnostic or therapeutic actions, always taking into account the patient's expressed wishes or, in its impossibility, that of their legal representative*⁵. CFM Resolution 1,995/2012 establishes the rules for using ADs *as the set of wishes, previously and expressly expressed by the patient, regarding care*

*and treatments that they want or not to receive at a time when they cannot express freely and autonomously their will*⁶.

In Brazil, palliative care has already been understood as a strategy against clinical scenarios in which the therapeutic possibilities available to deal with specific pathologies have disappeared⁷. It is currently understood as a multidisciplinary approach that improves the quality of life of patients and their families when dealing with life-threatening illnesses, aiming to avoid and reduce suffering by identifying, evaluating, and addressing pain and other symptoms that can affect them⁷.

Currently, ADs are considered a fundamental component of healthcare planning, used as a resource mainly by palliative care teams⁷. They are recognized as a means of ensuring that individual desires and values are respected, offering people suffering from a serious, incurable illness the opportunity to maintain control over their medical decisions and ensure that their preferences are considered when they most need them^{2,3}.

Thus, the application of palliative care and ADs is inseparable⁸ given the interconnection by the concern to respect patient autonomy and desires, seeking to overcome the biomedical understanding, in which a patient's health is understood as the absence of disease⁹, and working on an approach based on comprehensive care for the individual. Thus, there are more guarantees that the work provided meets the patient's values, avoiding therapeutic obstinacy and iatrogenesis and promoting an approach centered on the assisted person and their family^{8,10}.

Patients, family members, and healthcare professionals and/or students must work together to promote dignity, autonomy, and quality of life for the sick person^{8,10}. Open communication, information sharing, mutual understanding, and establishing care goals aligned with patient preferences form a collaborative approach that improves the quality of care. Furthermore, it promotes the therapeutic alliance between the parties involved, achieving better health results^{8,10}.

Given the importance of involving this triad in care and its benefits to patients with incurable and life-threatening diseases^{8,10}, this study aims to investigate the understanding that students,

healthcare professionals, patients, and caregivers have on the topic, according to the scientific productions reviewed here. Thus, the study will investigate how ADs have been conceptualized in the paradigm of the palliative approach, identifying convergences and divergences in the discourses found and discussing how this worldview can affect the quality of care offered in healthcare institutions⁸.

Method

Data collection

Given the complexity of the topic and the different methodological approaches used in health to investigate reality, an integrative literature review was chosen as the analysis tool¹¹. It allows a broad understanding of what is produced from different theoretical and methodological perspectives, considering the cross-sectional character of this field of studies and the multiple possibilities that can be used to explore it¹³.

Integrative reviews are a comprehensive methodological approach to obtain a broad understanding of the topic. It combines information from theoretical and empirical literature, covering a wide range of purposes, such as defining concepts, reviewing theories and evidence, and analyzing methodological issues related to the proposed theme¹². From this, the six phases of construction of the integrative review were followed:

1. Preparation of the guiding question;
2. Database search;
3. Data collection;
4. Critical analysis;
5. Discussion of results;
6. Presentation of the integrative review^{12,13}.

Data collection occurred between October and November 2022. Searches were carried out on the Journal Portal of the Coordination for the Improvement of Higher Education Personnel (CAPES), the Virtual Health Library (VHL), and the National Library of Medicine (NLM) search bank, PubMed, which have access to LILACS (Latin American and Caribbean Health Sciences Literature), SciELO (Scientific Electronic Library Online), and MEDLINE (Medical Literature Analysis and Retrieval System Online) databases, respectively.

When selecting references, all descriptors were used with the Boolean operators "OR" and "AND." The following descriptors were applied to the Brazilian platforms to adapt to the specificities of each portal and reach the desired literature: "diretivas antecipadas de vontade," "diretivas antecipadas," "testamento vital," and "cuidados paliativos" (Chart 1). Finally, "advance care planning," "advanced care," "living will," "advance directives planning," "palliative care," and "brazil" were used in the North American database (Chart 1).

Chart 1. Search platforms and search syntax

Search Platforms	Search details
CAPES Journal Portal	tw:("diretivas antecipadas de vontade" OR "diretivas antecipadas" OR "testamento vital" AND "cuidados paliativos") AND db:("SCIELO") AND (year_cluster:[2013 TO 2023])
Virtual Health Library	tw:("diretivas antecipadas de vontade" OR "diretivas antecipadas" OR "testamento vital" AND "cuidados paliativos") AND (collection:("06-national/BR" OR "05-specialized") OR db:("LILACS" OR "MEDLINE")) AND (year_cluster:[2011 TO 2023])
PubMed	tw:("advance care planning" OR "advanced care" OR "living will" AND "palliative care" AND "brazil" [db: "MEDLINE"])(year_cluster:[2011 TO 2023])

Eligibility criteria

Original scientific articles published between 2014 and 2022 that researched the topic were included, which used qualitative and quantitative

methodologies without restriction on the type of study design. The period was chosen based on the first article published in the databases operated in the investigation. The choice to encompass

different research methodologies is justified by the main objective of this study, which is to investigate the general perception of the care triad (patients, caregivers, health professionals and/or students) on the issues discussed here.

The following were included: 1) complete articles; 2) studies produced with Brazilian populations, both in English and Portuguese; 3) materials that discuss the perception of at least one of the target populations (patients, family members, and health professionals and/or students); 4) published between 2014 and 2022; 5) in a journal with Qualis classification A1, A2, A3, A4, or B1. The following exclusion criteria were used: 1) theses, monographs, dissertations, editorials, books, or any other type of written work on the topic other than research articles; and 2) not mentioning ADs as a central theme.

The choice of these inclusion criteria is justified by the scarce production on the subject, given the current situation of the proposed topic, whose first publication in the databases used was only made in 2014. Thus, to gather information suitable for this integrative review and preserve the methodological rigor of this work, in the prior selection of the material, journals that

did not present the desired Qualis rating were excluded¹³. Finally, the importance of safeguarding academic research with quality references is highlighted, selecting journals according to the classification carried out in the last four years by the Plataforma Sucupira¹⁴.

Data analysis

Sixty references were found, of which 20 came from MEDLINE, 23 from LILACS, and 17 from SciELO. From there, all abstracts were read and screened. Based on the exclusion criteria, 19 articles were discarded from MEDLINE, 11 from LILACS, and seven from SciELO. Fifteen duplicate SciELO articles were also checked and eliminated.

Most exclusions in MEDLINE were based on the divergence of nationality in the populations studied, which in this study is limited to Brazilian healthcare teams, patients, and caregivers. From SciELO and LILACS results, expanded abstracts, book chapters, theses, dissertations, and research with a purely philosophical and theoretical approach were excluded. At the end of the data analysis, eight articles were selected (Chart 2).

Chart 2. Identification and selection of articles for analysis



Results

Of the eight articles presented, four address patients, whereas five address students and healthcare professionals. Of these, two include caregivers and family members in the sample. The points of interest for this review were described to present these results in concisely and objectively. Title, author, and year were

indicated, in addition to the main objective of the study identified. The type of methodology used was also included, with three quantitative studies, two qualitative, and three with a qualitative and quantitative proposal. Finally, the definition used by the article to conceptualize ADs and the main contributions mentioned by the authors were prioritized. Chart 3 below describes the articles used in this review:

Chart 3. Presentation of results

Author (year); article title	Objective	Type of study/ participants	Conceptualization of ADs	Study contributions/ results
Silva and collaborators, 2015. <i>Conhecimento de estudantes de medicina sobre o testamento vital</i>	Assess the understanding of medical students at the State University of Pará (UEPA) about LW and decisions involving the end of life.	Descriptive cross-sectional study with a qualitative and quantitative nature; students (n=238) interviewed using a ten-question questionnaire.	Document written by a person in full possession of their mental faculties. Its purpose is to specify the care, treatments, and procedures they wish or not to receive when affected by a serious illness and cannot freely express their wishes.	Only 8% of students clearly understood the meaning of "living will." Despite this, after listening to the definition of ADs provided by the researchers, 92% declared that they respected the provisions of the living will.
Moreira and collaborators, 2017. <i>Testamento vital na prática médica: compreensão dos profissionais</i>	Study the opinion of resident physicians regarding inserting the patient's ADs or LW in medical practice.	Exploratory study of a qualitative nature with 36 physicians interviewed.	Document expressing the types of treatment the patient wishes to receive from healthcare professionals and caregivers during the terminal stage of life, recorded with mental lucidity and complete autonomy to deliberate about themselves, and with preserved quality of life.	Most physicians interviewed believe that LW is an instrument capable of guaranteeing a dignified death. Thus, they defend the creation of legal provisions that regulate formal use in Brazil.
Comin and collaborators, 2017. <i>Percepção de pacientes oncológicos sobre a terminalidade da vida</i>	Analyze the perception of cancer patients regarding the end of life.	Descriptive study using a questionnaire for oncology patients (n=100).	Document that records the wishes of how sick people would like to be treated when they are at the end of their lives, allowing them to lead their dying process and have dignity at that moment.	85% of participants were unaware of LW/ADs, 81% of palliative care, and 70% of the do-not-resuscitate order. The need to encourage discussion about terminal illness during patient care was verified.
Gomes and collaborators, 2018. <i>Diretivas antecipadas de vontade em geriatria</i>	Evaluate the understanding of elderly companions, professors, and medical students on the definition and implementation of ADs.	Cross-sectional descriptive study of a quantitative nature, in which companions of older people (n=66), professors (n=60), and medical students (n=72) were interviewed (n=72).	The ADs represent the patient's willingness to undergo medical treatment through the LW and the lasting mandate.	Elderly companions proved to be the group with the slightest knowledge about the topic. 40% of those interviewed demonstrated their intention to register ADs, with the majority being students to whom the concept was introduced.

continues...

Chart 3. Continuation

Author (year); article title	Objective	Type of study/ participants	Conceptualization of ADs	Study contributions/ results
Scottini and collaborators, 2018. <i>Direito dos pacientes às diretivas antecipadas de vontade</i>	Investigate the knowledge that patients with terminal illnesses had about their diagnosis, prognosis, and the possibility of recording their wishes at the end of life in the form of ADs.	Cross-sectional and descriptive study of a qualitative and quantitative nature conducted with patients (n=55) diagnosed with terminal illnesses.	Document that records the wishes of how sick people would like to be treated in terminal conditions, allowing them to lead their dying process and have dignity in this unique moment of their existence.	Most patients with preserved mental functions were found to have good knowledge of the disease diagnosis (95%). However, a significant number of these (69%) were never instructed by reference professionals to perform their ADs.
Chaves and collaborators, 2021. <i>Cuidados paliativos: conhecimento de pacientes oncológicos e seus cuidadores</i>	Verify the perception of palliative care, ADs, and do-not-resuscitate orders of cancer patients and their caregivers and their relationship with healthcare professionals.	Descriptive, quantitative study conducted with cancer patients (n=100) and caregivers (n=100) using a form.	The ADs are a set of desires, previously and expressly expressed by the patient, about the care and treatments that they want or not to receive at the time when they are unable to express, freely and autonomously, their wishes.	While most patients and caregivers report good medical support, most of them are unaware of terms such as "Palliative Care" (78%), "do not resuscitate order" (85%), and "living will" (96%).
Dias and collaborators, 2022. <i>Advance care planning and goals of care discussion: the perspectives of Brazilian oncologists</i>	Explore the difficulties faced by Brazilian oncologists in preparing ADs.	Cross-sectional study with a quantitative and qualitative approach developed to identify Brazilian oncologists' barriers to discussing goals of care and ADs.	ADs are an instrument that allows respect for patient autonomy. It involves exploring values, beliefs, and what is most important to each person: ensuring agreement between the clinical care received and the patient's wishes.	Identifying barriers that limit discussion of ADs and early referrals to palliative care can undoubtedly help prioritize the next steps for future studies aimed at improving ACP and help physicians better support patients through shared decision-making based on the patient's values and experiences.
Fusculim and collaborators, 2022. <i>Diretivas antecipadas de vontade: amparo bioético às questões éticas em saúde</i>	Analyze the current context of ADs implementation in Brazil based on the participants' perceptions.	Exploratory, cross-sectional study with a quantitative approach, with the participation of physicians (n=90) and nurses (n=51).	It involves understanding values, beliefs, and what is most important for each person: ensuring agreement between the clinical care received and the patient's wishes.	Professionals with training in palliative care had greater knowledge of ADs and greater ease in accepting and implementing them. Among those who responded that they were afraid of applying the ADs, the majority said that this concern was related to legal issues, and the others to ethical issues.

A decision was made to group the data into different topics to describe better the materials found and understand the perception of the care triad (patients, caregivers, health professionals and/or students) on the topic investigated. Therefore, considering that most articles include students and healthcare professionals in their sample, and only two interviewed companions, priority was given to categorize the discussion based on the convergence of results and interpretations made in the research revised, resulting in three categories:

1. Understanding the concept of ADs;
2. Knowledge of students and healthcare professionals about ADs;
3. Knowledge of patients and caregivers about ADs.

Discussion

Understanding the concept of ADs

This group contains the most common definitions and interpretations of ADs. From this, all the articles selected in this review, except Dias and collaborators¹⁰ and Chaves and collaborators¹⁹, were noted to equate the concepts of ADs and LW, attributing legal and juridical content to the definitions.

Most articles^{8,10,11,15,18} use terms such as “legal representative” or “proxy” when addressing caregivers and family members responsible for claiming ADs, in addition to the lack of national legislation appearing as a recurring concern for professionals—especially physicians. These factors, added to the apparent lack of knowledge regarding the CFM’s guidelines and the jurisdiction of the topic, delay and complicate the application of the ADs. Thus, the literature on the subject conveys the generalized understanding that ADs can only be implemented as special documentation written by lawyers and legitimized by a notary.

This interpretation, if absorbed by healthcare teams, may create barriers by making the understanding difficult for professionals, patients and caregivers. After all, good physician-patient communication, with the continuous creation of these records in the medical record, is sufficient for the construction of ADs, as the record in an institutional environment already meets the

requirements to configure a legal document that directs conduct both to feed the medical record during hospitalization and for outpatient care, considering that the profile of patients with more benefits associated with this approach tends to undergo regular medical follow-up⁷.

Knowledge of students and healthcare professionals about ADs

This topic discusses studies conducted based on the knowledge of medical students, physicians, and nurses in generalist areas and those who deal directly with older patients and those with chronic illnesses.

In Gomes and collaborators¹¹, 77% of medical professors who work in geriatrics outpatient clinics reported that they were unaware of ADs, 13% declared that they had an idea, and only 10% responded affirmatively. Within this same 10% group are those aware of the Brazilian regulations on ADs for physicians and know there is still no legislation on the subject. Of the medical students who responded to the same questionnaire, 62% did not know, 20% did, and 18% had some idea of the concept.

In another study with similar results, conducted by Silva and collaborators¹⁵, only 6% of the medical students interviewed clearly understood the term “living will,” whereas 33% reported partial understanding; 11% of respondents were completely unaware of the subject, and 50% chose not to answer the question. When clarified about the concept of LW and questioned about its applicability, the majority stated that they would respect the patient’s wishes. However, it is necessary to consider that the ethical issues and dilemmas exposed during medical graduation are often approached from the deontological perspective of the Code of Ethics, so critical reflection on values linked to the experience of clinical practice does not receive adequate encouragement¹³.

In the most recent study, published by Fusculim and collaborators⁸ in 2022, of the 143 nursing and medical professionals, 111 claimed to know about ADs, i.e., 77% of participants. Positive results were presented for understanding ADs and palliative care compared to the previously mentioned studies published in 2015 and 2018.

It is valid to say that, despite the positive rate, most physicians interviewed come from the most diverse specialties. Few have actual contact with palliative approaches and the construction of ADs in their clinical practice. However, it is notable that discussions involving end-of-life guidance became more common after the COVID-19 pandemic, popularizing some concepts and procedures in the area for professionals working in another sphere²⁰.

Finally, Dias and collaborators¹⁰ interviewed 66 oncologists from different Brazilian regions and identified that most of them knew the concept of ADs. However, despite being in constant contact with patients who have a poor prognosis, they show little availability to apply palliative care, and consequently, ADs, as a physician or a palliative team, do not follow them up. The exception to this approach are oncologists with some specialization or experience in palliative care.

Knowledge of patients and caregivers about ADs

In their study in a geriatrics outpatient clinic, Gomes and collaborators¹¹ questioned 66 companions of older people about their knowledge of ADs. Only 3% of participants were aware of ADs, and only 2% were aware of the resolution that regulates them in Brazil⁶. After being introduced to the concept, 30% of companions indicated that their family members, outpatients, had already discussed the paths to treatment when they could not make decisions autonomously.

In their study on the perceptions of patients with cancer about terminal illness, Comin and collaborators¹⁸, 81% declared that they were unaware of palliative care, whereas 85% did not know LW or ADs. Furthermore, 95% of participants stated that they did not receive any prediction about their remaining lifespan from their attending physician.

That said, it is known that clearly disclosing the prognosis is the physician's responsibility, as established in Art. 34 of the Code of Medical Ethics⁵. However, only half of the patients had conversations about their vital prognosis with the physician, and almost all (95%) did not receive any life expectancy, which makes it challenging to plan the future in cases of serious illnesses.

Finally, Chaves and collaborators¹⁹ conducted a study with 200 participants, being 100 patients with cancer and 100 informal caregivers. Of the participating patients, 78% declared unaware of the term "palliative care," and 96% stated that they were unfamiliar with LW. After these initial questions, the interviewers explained the meaning of each term, and 60% reported interest in building their ADs. Concerning the caregivers, who may or may not have a family connection with the patient, 63% said they were not close to palliative care, and 81% said they had never been informed about LW.

Final considerations

With the increase in the average population age and the consequent increase in chronic diseases, healthcare teams must adjust to a new reality in which end-of-life becomes increasingly common. In this context, ensuring a "quality death" for patients should be a priority rather than simply maintaining life at all costs^{8,10,19}.

From the legal perspective under which advance directives are exposed in this review, it is feared that the legalistic approach may alienate patients who do not have easy access to this knowledge. Furthermore, despite lacking specific legislation, this topic and its debates are not new to jurists, who already rely on jurisprudence based on the regulation of CFM⁴⁻⁶ and the countless precedents that point toward ADs, even when not documented²⁰.

Research on the knowledge of patients and caregivers found similar results. Therefore, it is essential to highlight that, although many patients say they trust their relationship with physicians, they and their families often do not receive appropriate guidance on the implications of the disease, lifespan, and the options available to mitigate symptoms and improve the quality of life. In this scenario, they end up being deprived of the ability to make decisions based on the process of facing death with dignity^{11,18,19}.

According to the National Supplementary Health Agency (ANS)²¹, only around 23% of Brazilians have some type of private health plan, whether medical or dental. Furthermore, given

the current social inequality in the country, with a population that is primarily served by the Unified Health System (SUS), it is necessary to offer tools to healthcare professionals to mobilize their engagement towards knowledge and application of ADs to guarantee a therapeutic project that takes into account the socioeconomic conditions, values, and spirituality of each person served.

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Lizandra Saraiva Borges was responsible for developing the hypothesis, collecting data, and writing the manuscript. Maria Juliana Vieira Lima guided the research, corrected the method, and critically reviewed the original text.

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