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# Advance directives of will: bioethical support for ethical health issues

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## Abstract

This is an exploratory, cross-sectional study with a quantitative approach, with the participation of 143 physicians and nurses. An electronic questionnaire was applied on an online platform to analyze the current context of implementation of advance directives of will in Brazil from the perception of the participants. The results showed that professionals with training in palliative care have greater knowledge of advance directives ($p<0.05$) and feel easier to accept and implement them ($p<0.001$). Among those who answered that they were afraid to apply the advance directives (n=27), 15 reported that this concern is related to legal issues, and four to ethical issues. We conclude that knowing what the directives are makes the process of deliberation with the patient simpler, and knowledge in bioethics is one of the pillars to support the decision of professionals when choosing the best conduct to be adopted.

**Keywords:** Bioethics. Advance directives. Nursing. Medicine. Palliative care.

## Resumo

**Diretivas antecipadas de vontade: amparo bioético às questões éticas em saúde**

Trata-se de estudo exploratório, transversal, de abordagem quantitativa, com participação de 143 médicos(as) e enfermeiros(as). Foi aplicado questionário eletrônico em plataforma on-line, objetivando analisar o contexto atual de implementação das diretivas antecipadas de vontade no Brasil a partir da percepção dos participantes. Os resultados mostraram que os profissionais com formação em cuidados paliativos têm maior conhecimento das diretivas antecipadas ($p<0,05$) e maior facilidade em aceitá-las e implementá-las ($p<0,001$). Dentre aqueles que responderam ter receio de aplicar as diretivas antecipadas (n=27), 15 referiram que essa preocupação está relacionada a questões legais, e quatro, a questões éticas. Conclui-se que saber o que são as diretivas torna mais simples o processo de deliberação com o paciente, sendo os conhecimentos em bioética um dos pilares para embasar a decisão de profissionais no momento de escolher a melhor conduta a ser adotada.

**Palavras-chave:** Bioética. Diretivas antecipadas. Enfermagem. Medicina. Cuidados paliativos.

## Resumen

**Directivas anticipadas de voluntad: apoyo bioético a aspectos éticos en salud**

Este estudio es exploratorio, transversal, de naturaleza cuantitativa, en que participó 143 médicos(as) y enfermeros(as). Se aplicó el cuestionario electrónico en una plataforma en línea para analizar el actual contexto de aplicación de las directivas anticipadas de voluntad en Brasil desde la percepción de los participantes. Los resultados mostraron que los profesionales con formación en cuidados paliativos tienen mayor conocimiento de las directivas anticipadas ($p<0,05$) y mayor facilidad para aceptarlas y aplicarlas ($p<0,001$). De los que respondieron tener miedo a aplicar las directivas anticipadas (n=27), 15 dijeron que esta preocupación estuvo relacionada con aspectos legales, y cuatro, con aspectos éticos. Se concluyó que saber cuáles son las directivas simplifica el proceso de deliberación con el paciente, así el conocimiento en bioética es una de las bases que fundamenta la decisión de los profesionales al considerar la mejor conducta.

**Palabras clave:** Bioética. Directivas anticipadas. Enfermería. Medicina. Cuidados paliativos.

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Advance directives (AD), which this study understands as living wills, according to Dadalto's perspective[1], provide patients with the possibility of having their will respected at the end of their lives. Thus, it is understood that it is the exercise of what is known as prospective autonomy, in which patients outline guidelines for future treatments by analyzing the facts and establishing the objectives they consider possible to achieve. In a prospective reflection, it is the process, in the studied case, which leads to outcomes aiming to refer patients to treatment in the end of their lives[2].

In this sense, AD enables patients to accept, refuse or impose reasonable limits for procedures to which they wish to be subjected if terminally ill or at the end of their lives, representing patients' freedom to express their desires[3,4].

In view of this perspective, bioethics proposes questions on respecting these patients' autonomy and dignity regarding clinical decision-making, which must comply with ethical norms. It is considered that, at the end of patients' lives, healthcare providers often need to make decisions which generate bioethical conflicts. This occurs, for example, when the desire to no longer continue with life-prolonging treatments is manifested, considering that living is different from being alive.

It is important to highlight that this study begins with medicine and nursing professionals' perspective, specifically. This warning is necessary since it is based on the ethical norms of these professional categories—but not limited to them—using the existing concepts and doctrines which several Brazilian researchers have described. This study is based on empirical research conducted with healthcare providers and, rather than intending to discuss the legality of AD, it only aims to highlight the bioethical support to the decisions of healthcare providers in their daily practice.

This study presents the following questions: what is the current context of AD implementation in Brazil from the perspective of medical and nursing professionals and what are the potential contributions of bioethics to it? It was established the hypothesis that medical and nursing professionals' understanding of AD is essential for its implementation, which knowledge in bioethics can facilitate.

Thus, this study aimed to analyze the current AD implementation context in Brazil, based on the knowledge of medical and nursing professionals, and to identify how bioethics may contribute to its implementation.

## Method

This is an exploratory, cross-sectional, quantitative study, registered on Plataforma Brasil and approved by the Pontifícia Universidade Católica do Paraná Research Ethics Committee. Data were collected between December 2, 2020, and April 30, 2021, with physicians and nurses from all Brazilian macroregions. We highlight the importance of this empirical research and its articulation with the chosen theoretical framework, which aims to provide answers to the questions guiding this study.

This research was conducted by applying an online questionnaire, via Google Forms, with 23 questions addressing the knowledge of professionals about the concept and implementation of AD. Medical and nursing professionals from the authors' Brazilian contact networks were contacted by WhatsApp and Telegram electronic messages. At the end of the message, it was requested that the invitation be forwarded to other healthcare providers who belonged to guests/participants' contact network. This method of data collection is known as virtual snowball[5]. All participants over 18 years of age, of all genders, who were physicians and nurses from the whole Brazilian territory were included.

The statistical program SPSS, version 20.0, was used for data storage and tabulation and descriptive statistics. The Pearson's chi-squared test was employed to measure the correlation between variables. A 5% significance level was used in all tests ($p<0.05$).

## Results

In total, 143 professionals answered the questionnaire of this study, of which we excluded two since they worked outside medicine or nursing, resulting in 141 participants. Table 1 lists subjects' characteristics.

**Table 1.** Participants' gender, training, age group, time of activity, area of specialty/performance, and region in which they reside (n=141)

| Characteristics | n | % |
|---|---|---|
| Gender | | |
| Male | 30 | 21.3 |
| Female | 111 | 78.7 |
| Training | | |
| Medicine | 90 | 63.8 |
| Nursing | 51 | 36.2 |
| Age group | | |
| 20 to 35 years | 53 | 37.6 |
| 36 to 50 years | 55 | 39 |
| 51 to 65 years | 27 | 19.1 |
| Over 65 years | 6 | 4.3 |
| Professional experience | | |
| 0 to 10 years | 61 | 43.3 |
| 11 to 20 years | 36 | 25.5 |
| 21 to 30 years | 23 | 16.3 |
| Over 30 years | 21 | 14.9 |
| Region of the country | | |
| South | 86 | 61.0 |
| Southeast | 33 | 23.4 |
| Midwest | 10 | 7.1 |
| Northeast | 11 | 7.8 |
| North | 1 | 0.7 |
| Specialty/main performance | | |
| Palliative care/ICU | 34 | 24.1 |
| Other | 25 | 17.7 |
| Geriatrics | 17 | 12.1 |
| Pediatrics | 10 | 7.1 |
| Gynecology/obstetrics | 7 | 5,0 |
| Nursing | 6 | 4.3 |
| Medical clinic | 5 | 3.5 |
| Family medicine | 5 | 3.5 |
| Occupational medicine | 4 | 2.8 |
| Orthopedics | 4 | 2.8 |
| Urology | 3 | 2.1 |
| Pulmonology | 3 | 2.1 |
| Public Health | 3 | 2.1 |
| Anesthesiology | 2 | 1.4 |
| Hematology | 2 | 1.4 |
| Psychiatry | 2 | 1.4 |
| Cardiology | 2 | 1.4 |
| Dermatology | 2 | 1.4 |
| Urgency/emergency | 1 | 0.7 |
| Oncology | 1 | 0.7 |
| Endocrinology | 1 | 0.7 |

Once we knew the participants' demographic characteristics, we asked questions about the object of this research, that is, knowledge and opinions about AD. Among participants, 115 stated having knowledge about the term AD and 26, that they lacked it; 76 claimed knowing how to do or register AD and 26, failed to; and 133 stated believing that people need to have AD.

Moreover, 90 participants showed interest in writing their own AD and 124, in acquiring new knowledge on the subject. Of these, 74 claimed they would like to have greater knowledge of the legal issues of AD; 29, on ethical ones; and 19, on clinical ones.

An important result was that 85 participants understood that physicians should start the dialogue about AD with patients, followed by answers that patients themselves should initiate the subject (n=23); caregivers or family members (n=21); nursing professionals (n=8); and four reported that other unspecified people should initiate it.

Regarding professionals' knowledge about palliative care, 105 stated having it. Of these, 31 claimed having started their approach with the theme during medical residency; three, in multiprofessional residence; 27, in graduate school; 20, in short courses; six, in internships; and 45, via other unrelated situations. When asked about their effective performance in palliative care, 51 stated working in it; 81, in other areas, and nine failed to answer.

Table 2 shows factors related to participants' knowledge of the term AD.

**Table 2.** Factors related to participants' knowledge of the term advance directives

| Association factors | Knowledge of the term AD | | *p* |
|---|---|---|---|
| | Yes (n) | No (n) | |
| Working in Southeastern Brazil | 33 | 0 | 0.015 |
| Knowledge in PC | 102 | 3 | <0.001 |
| Initiation of contact with PC in medical or graduate residency | 27 | 0 | <0.001 |
| Main area of activity in PC and/or ICU | 33 | 1 | 0.001 |
| Main area of expertise in geriatrics | 17 | 0 | 0.001 |
| Knowledge of the CFM Resolution 1,995/2012 | 83 | 0 | <0.001 |
| Knowledge of how AD is made/registered | 77 | 0 | <0.001 |

continues...

**Table 2.** Continuation

| Association factors | Knowledge of the term AD<br>Yes (n) | <br>No (n) | *p* |
|---|---|---|---|
| Knowledge of how AD is implemented | 70 | 0 | <0.001 |
| Knowledge of people/ patients who have AD | 56 | 0 | <0.001 |
| Understanding that physicians should initiate the dialogue on AD | 76 | 9 | 0.019 |

*ICU: intensive care unit; PC: palliative care; Pearson Chi-Square, significance when* p<0.05

Table 3 shows factors related to participants' knowledge of AD implementation.

**Table 3.** Factors related to participants' knowledge of implementing advance directives (AD)

| Association factors | Knowledge on how to implement DAV<br>Yes (n) | <br>No (n) | *p* |
|---|---|---|---|
| Working in Southeastern Brazil | 25 | 8 | 0.018 |
| Knowledge in PC | 67 | 33 | <0.001 |
| Initiation of contact with PC in medical or graduate residency | 22 | 4 | <0.001 |
| Main area of activity in PC and/or ICU | 25 | 9 | <0.001 |
| Main area of expertise in geriatrics | 17 | 0 | <0.001 |
| Knowledge of the CFM Resolution 1,995/2012 | 66 | 13 | <0.001 |
| Know how to do and register AD | 65 | 7 | <0.001 |
| Knowledge of people/patients who have AD | 48 | 6 | <0.001 |
| Understanding that healthcare providers should initiate the dialogue on AD | 50 | 30 | 0.019 |

*ICU: intensive care unit; PC: palliative care; Pearson Chi-Square, significance when* p<0.05

Participants' fear of implementing AD was negatively associated with knowledge in palliative care ($p$=0.011); initiation of contact with palliative care in medical residency ($p$=0.001); mainly working in palliative care/intensive care ($p$<0.001); living in Southeastern Brazil ($p$=0.001); and knowledge of the CFM Resolution 1,995/2012 ($p$<0.001). There was also a statistically significant difference, with a small number of participants, among professionals over 65 years of age, when asked if they knew someone who has the declaration of the advance healthcare directive: within the universe of six people in this age group, five answered affirmatively ($p$=0.049).

When analyzing our results according to macroregion, we found the association of professionals from Southeastern Brazil with knowledge of AD ($p$=0.15); of the process of elaborating and registering AD ($p$=0.12); of other people who have advance healthcare directives ($p$=0.10); and of CFM Resolution 1,995/2012 ($p$=0.001). Professionals from Southeastern Brazil gave physicians the responsibility to start the conversation about AD ($p$=0.001). In Southern Brazil, participants attributed this responsibility to family members/caregivers ($p$=0.001).

The analysis showed that most professionals knew of AD (82% of participants) and reported knowing how to apply them (54%). It was remarkable participants' awareness that AD is the right of patient and should be respected.

Finally, it was verified that participants' characteristics, such as age and training length, showed no correlation with knowledge about the subject.

## Discussion

Technological advances in health extend life but it has been increasingly debated to the point in which end-of-life patients would have the right to prevent the use of new techniques, often with great physical, psychological, and emotional suffering for both patients and their families. In this context, it is imperative to discuss ways to preserve end-of-life patients' autonomy and dignity in the face of the healthcare process[6].

The issue of AD makes part of self-management explicit, that is, these prior instructions anticipate people's wills, making clear the therapeutic limits which must be undertaken if people can no longer express them at some point in their lives. AD not only deal with end-of-life desires but also manifest a prior desire which will affect patients when they are unable to make them freely and autonomously. AD involve six species: living will, durable power of attorney, non-resuscitation orders, psychiatric advance directives, directives for patients with dementia, and birth plans[7]. However, as already mentioned in this article, the expression AD is used for what is understood as a living will, according to Dadalto's perspective[1]. Thus, AD provide patients with respect for the possibility of having their will accepted and respected in their final moments.

Honoring sick people's self-determination is to give them the chance not to exercise their right to death but to contemplate themselves with dignity when their end is near[8]. In this scenario, patients are the main actors, who, in using their freedom to dispose of their well-being, choose to suspend treatments which only prolong their suffering.

In Brazil, understanding that applying AD occurs especially at patients' end of life justifies the association of knowledge in palliative care with that of AD, which is statistically significant in this study. Respect for patients' will, determinations, and desires includes recognizing and responding to the needs of patients and their family members' with a broad and transdisciplinary view. The achievements of medical technology are recognized but a gradual and balanced transition is made between legitimate attempts to maintain life when there are real chances of recovery and the palliative approach of symptom control, without ever disregarding the dimension of human finitude[9].

Palliative care is knowledge which most participants acquired after traditional academic training (graduation), during medical or multidisciplinary residency, postgraduate discipline, and various courses. Although there is still little offer in hospital institutions and, consequently, little access for the population to this care, it is noted that the number of specialized health professionals is growing, as is the interest of the media and society in this matter[10].

Knowledge in palliative care sets providers apart from others. An analysis of answers by Brazilian macroregion found extremely relevant and interesting results to be discussed, such as those from professionals from the Southeast, which we already mentioned. It should be considered that this region has the largest number of graduate courses in palliative care in the country, extendable to multidisciplinary teams. This leads us to believe that these professionals have more knowledge about palliative care and better conditions to talk about AD with patients, besides better knowing the theme.

But if those who work with palliative care can properly apply patients' AD, what is missing for the others? They are likely to lack theoretical support since this basis arises after graduation, with the search for qualification on the subject. It is necessary to hold higher education institutions and professionals accountable for learning and updating themselves, as well as regulatory and supervisory entities, such as the Federal Council of Medicine (CFM) and the Federal Nursing Council (Cofen), for disclosing the regulation of the practice. Healthcare must have a bioethical support for professionals' decision-making with patients. Knowledge in palliative care is essential for end-of-life care.

Regarding AD knowledge, this research found an expressive and relevant results for nursing education, significantly associated with knowledge on AD. Since respect for AD is expressly recognized in the code of ethics of the category[11], this device supports patients with AD in the face of nursing professionals' ethical issues on the subject, establishing a situation of certainty regarding the will outlined by patients.

Nursing professionals working on the front line of care and in constant contact with patients have a vision of the individual that goes beyond the sometimes superficial and merely professional relationship of care. Thus, closer coexistence contributes to further develop interpersonal relationships, providing an integral knowledge of patients, their life history, desires, and fears and, with the support of the ethical norm, the necessary certainty for applying AD without further doubts.

Moreover, nursing professionals have greater freedom to ask about the existence of AD. For this reason, it is important to insert the discussions on the subject in the formative process of these professionals, develop studies on the theme, and bring bioethics as a tool for healthcare practice, especially at the moment of patients' decision.

On the other hand, it surprised us that many medical participants were unaware of CFM Resolution 1,995/2012, which deals with AD. This resolution highlights, in its article 2, paragraph 5, that, if patients' AD is unknown or there is no designated representative or available family member—or in case of lack of consensus among these—physicians should turn to the bioethics committee of the institution and, in its absence, to the Regional Council or to CFM's medical ethics committee[3].

Thus, if the deontological standard applicable to physicians is clear in informing about AD, their ignorance of this standard can generate difficulties in its application. The knowledge of CFM Resolution 1,995/2012 showed a significant result regarding the absence of fear in applying AD.

If the ethical norms for medical professionals support them regarding the adoption of measures in the absence of AD, there should be more tranquility regarding their acceptance in cases in which patients have AD. The resolution of unambiguous application for physicians very comprehensively clarifies the issue of AD or its absence but physicians often lack this knowledge. Despite the significant number of physicians who claimed to know the resolution, we stressed the fact that, since the resolution in question is a deontological standard applicable to physicians, there would be a need for all physicians to know it.

Resolution CFM 1,995/2012 also establishes, in paragraph 4 of Article 2, *that physicians will register, in patients' medical records, the advance directives which were directly communicated to them by patients*[12], which seems to meet the role that physicians have in AD in other countries, and more, with the function of this professional[8].

Furthermore, it should be considered that, currently, *there is an empowerment of patients who, aware of their rights, demand their right to receive complete and clear information about their health condition to be able to participate in the decision-making process on the procedures to be adopted*[13]. Thus, the principle of patient autonomy gains prominence[14]. Therefore, the need arises to search for elements in bioethics, within what is known as bioethics of deliberation, which help to understand the process of exposure and implementation of AD.

The deliberation of ethical conflicts is understood as weighing values and duties within this fact. Its scope is to dialectically solve moral conflicts among those involved, achieving a thoughtful and prudent solution. To this end, the aim evades an ideal solution, seeking a reasonable one, with a critical view distanced from the idealistic or utilitarian view[15]. Deliberation is not done abstractly; it analyzes the practical problem, prudently values conducts, and refrains treating ethical conflicts as dilemmas, which must be statistically analyzed, mathematically measuring the pros and cons of each argument[16].

From the perspective that, in healthcare, proximity is necessary so those involved develop trust in one another, deliberation constitutes a systematized and contextualized itinerary to analyze events in a hermeneutic endeavor, an interpretation of events in the whole of life and as part of this[15]. Ethical responsibility also precedes the conditions of choice. Thus, healthcare providers, as recipients of AD, were elected by patients as the recipient of their wishes and must take responsibility for them and enforce their decisions when individuals can no longer express their will.

Deliberation, conceived regarding human rights, valuing freedom, equality, and critical solidarity and denying intolerance means an ethics based on deliberative competence as a means of dealing with moral conflicts[16].

Thus, AD are, among several of the bioethical issues at daily healthcare practice, one of the situations in the professional-patient relationship which seeks quality of life related to healthcare. A possibility of changing providers' attitude, in the sense of a deliberation from a collective coexistence, seems to pass by the configuration of a new professional excellence which encompasses critical solidarity and commitment to the other in new forms (councils, committees, and health teams), breaking the old Hippocratic paradigm, class separatism, and private interests overlapped with public ones[17].

Once again, it is shown that bioethical support can help professionals to act on delicate issues, such as accepting and implementing AD, since this support demystifies issues such as the possibility of future ethical, moral or judicial questioning, which are often obstacles to its application.

When it is verified, in our research results, that most professionals understand that physicians should start the conversation about the subject, it once again turns to the basic question of discussing the deliberative process in bioethics and training physicians on AD. We find a need, in these cases, to abandon the traditional paternalistic medicine model and embrace the new reality in which patients are autonomous, able to make their own decisions (assisted by health professionals), and never induced or convinced to adopt a treatment model.

Deliberation, by anticipating and projecting actions, enables human adaptation and its survival as a species, but it means, in addition to a simple adaptation to the natural environment, a responsibility, in view of the consequence of these actions, which elevates humans to moral beings. Transforming nature by work gives rise to the world of culture. Thus, *deliberation is not only based on biological selfishness as a generator of moral selfishness but also on altruism, which it considers in favor of the species* [18].

Another finding is that few participants reported knowing people who already have AD, which we expected, considering that the subject is not widely publicized and is unknown by a large portion of the population. However, there is an association between the knowledge of people who have AD and participants' age group (over 65 years of age). The situation may be relevant because older professionals tend to have seen many more cases of death in their professional lives and understand it more naturally. It is still possible that they know more people, perhaps due to their age, who have already expressed their intentions about the end of their lives.

It is observed that, a small number of participants fear applying AD but the issues which led them to manifest themselves in this sense drew our attention. In this group, most fear applying AD for legal reasons, probably due to their ignorance on the subject, lack of a specific standard, and absent bioethical support regarding the legality of patients' decision and, consequently, fear of lawsuits.

For this group, bioethics can help support a deliberative itinerary, analyzing the fact within patients' context and inserting subjects in decision-making in an enlightened way, after discussing with professionals who assist them with their prognoses and forms of treatment. Thus, at the end, it is understood that the decision regarding AD was consciously taken, and there is no reason for professionals to have doubts as to the validity and/or legality of their choice.

Another important finding, found in this research, was the fact that most participants know of palliative care but when it comes to applying AD, this number significantly drops. This shows that, although medical and nursing professionals know the subject and seek qualification about it, they still ignore how to apply AD when they exist.

This finding initiates the answer to the guiding question of the study: although most participants have knowledge about palliative care, most fail to know how to respect the information contained in decision-making within AD. Among those who know the advance directives, most have no fear of applying them. Also, an extremely positive result was that most participants expressed interest in acquiring new knowledge on the subject, considering those related to legal issues as more important, followed by ethical and clinical issues.

Our results show that the implementation of DAV in Brazil is progressing. However, the lack of regulation and basic training on bioethical concepts represent the main fears indicated by healthcare providers.

## Study limitations

This study contains some limitations. Its first one is the restriction of research to medical and nursing professionals, that is, the results obtained start exclusively from the view of these professionals, and not from multidisciplinary teams as a whole.

Its second limitation lies in the fact that its normative basis occurred in the ethical norms on the subject of AD—CFM and Cofen resolutions—which, although criticized, are the normative elements available for the legal basis on the subject. It is important to highlight that the use of these regulations as a basis was a choice for this study precisely because our target audience consisted of physicians and nurses and, thus, CFM Resolution 1,995/2012 makes sense for the participants.

The third limitation relates to the restriction of this study in discussing only end-of-life AD, known as living will [7]. We made this choice because it is necessary to establish a specific goal to search for professionals' perception of AD within the context of end-of-life patients with diseases considered incurable and advanced.

Our fourth limitation refers to the professionals participating in the research, who, by identifying with the theme, mostly had some training in palliative care. This may, in a way, have contributed to a result which makes sense in the development of work and concepts within this universe, but which may fail to represent the general reality of healthcare practice, if it considered a group of professionals who fail to work with palliative care.

Finally, the restrictions imposed by the COVID-19 pandemic and the resulting overload of professionals prevented the participation of a larger number of people to further develop this research on the potential contributions of bioethics to AD implementation.

## Final considerations

This study observed that knowledge about AD is a reality for most participants and that it was directly linked to knowledge in palliative care. Nursing professionals showed greater acceptance regarding the application of AD than those in medicine. As professionals have more knowledge about palliative care, they are more likely to accept the implementation of AD.

This study confirmed its hypothesis that knowledge about ethical, clinical, and legal issues by medical and nursing professionals is essential for implementing AD and can be facilitated by knowledge in bioethics. Thus, expanding bioethics education, specifically in bioethics of deliberation, will support healthcare providers to apply AD broadly and safely regarding the correction of the adopted procedure.

Thus, knowledge in bioethics and palliative care, as part of the training of healthcare providers since graduation, may offer theoretical support to solve conflicts of interest and values, thus supporting health care practice and, consequently, the application of patients' AD.

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