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THE MORAL FIELD OF ADVANCE DIRECTIVE AND ITS REGULATION IN BRAZIL

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Abstract: Despite more than 50 years of existence and their recognized importance, advance directives (ADs) are still the subject of doubts and criticism. The original defect, the instability of decisions, and the argument of personal identity are some of them. In Brazil, this instrument is not regulated by federal law, although Resolution No. 1995/2012 of the Federal Council of Medicine and Resolution No. 41/2018 of the Ministry of Health are in force, contributing to its implementation and to studies in this area. This article proposes to 1st) investigate some doubts and criticisms about ADs, as they challenge their moral authority; 2nd) highlight the repositioning of ADs in the moral field; 3rd) suggest this moral field as a starting point for bioethical investigations on their regulation in Brazil.
The approach was philosophical/bioethical (analytical), according to Aristotle's position in *Nicomachean Ethics* on the scope of ethical research.
It is concluded that ADs can be more robust and effective if their moral field is that of the circumstances, where the manifestation provides the person with moral choices and actions that operate in a grey area, allowing health professionals and their representatives to interpret their wishes according to each situation.

Keywords: bioethics, advance directives, personal autonomy

El campo moral de la directiva anticipada y su regulación en Brasil

Resumen: A pesar de sus más de 50 años de existencia y de su reconocida importancia, las voluntades anticipadas (VA) siguen siendo objeto de dudas y críticas. El defecto original, la inestabilidad de las decisiones y el argumento de la identidad personal son algunos de ellos. En Brasil, este instrumento no está regulado por la ley federal, aunque están vigentes la Resolución Nº 1995/2012 del Consejo Federal de Medicina y la Resolución Nº 41/2018 del Ministerio de Salud, lo que contribuye a su implementación y a los estudios en esta área. Este artículo propone: 1º) indagar algunas dudas y críticas sobre los EA, ya que desafían su autoridad moral; 2º) poner de relieve el reposicionamiento de las VA en el campo moral; 3º) sugerir este campo moral como punto de partida para las investigaciones bioéticas sobre su regulación en Brasil. El enfoque fue filosófico/bioético (analítico), de acuerdo con la posición de Aristóteles en la *Ética a Nicómaco* sobre el alcance de la investigación ética.
Se concluye que las VA pueden ser más robustas y efectivas si su campo moral es el de las circunstancias, donde la manifestación proporciona opciones y acciones morales que operan en una zona gris, permitiendo a los profesionales de la salud y a sus representantes interpretar los deseos del paciente de acuerdo con cada situación

Palabras clave: bioética, voluntades anticipadas; autonomía personal

O campo moral de diretivas antecipadas* e sua regulação no Brasil

Resumo: A despeito dos mais de 50 anos de existência e de sua reconhecida importância, as Diretivas antecipadas de vontade (DAV) ainda são objeto de dúvidas e críticas. O vício de origem, a instabilidade das decisões e o argumento da identidade pessoal são algumas delas. No Brasil, este instrumento não possui regulamentação na legislação federal, embora estejam em vigor a Resolução n.º 1995/2012 do Conselho Federal de Medicina e a Resolução n.º 41/2018 do Ministério da Saúde que contribuem para sua implantação e para estudos nesta área. Este artigo propõe 1º) investigar as principais críticas às DAV, considerando que estas desafiam sua autoridade moral; 2º) indicar o reposicionamento das DAV no campo moral; 3º) propor esse campo moral como ponto de partida das investigações bioéticas sobre sua regulamentação no Brasil. A abordagem foi filosófica/bioética (analítica), considerando a posição de Aristóteles na obra *Ética a Nicômaco* acerca do alcance da investigação ética.
Conclui-se que as DAV podem ser mais robustas e efetivas se seu campo moral for o das circunstâncias, quando a manifestação propicie à pessoa escolhas e ações morais que operam numa zona cinzenta, permitindo que profissionais de saúde e seu representante interpretem suas vontades de acordo com cada situação.

Palavras-chave: bioética, diretivas antecipadas, autonomia pessoal

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Introduction

Advances achieved in health care, and in life in general, during the 20th century, such as the development of medical techniques and interventions, as well as improvements in the quality of life overall, have increased the capacity to maintain and prolong human life, even in adverse situations. However, this has not necessarily meant benefit for patients in health care, as for some it may characterise the lengthening of suffering and death. There is an inevitable conflict between what is technically possible and what is humane, and ethically justifiable, requiring actions by professionals who will balance these two rival positions. In this conflict there is also the tension between the claim of respect for the patient's autonomy —and his self-determination— and that which is carried out for his benefit, for his well-being (his best interests)*(1-4)*. Such conflicts can still express two rival positions in dispute: the imperative recognition of the individual right to self-determination and the radical defence of human life*(4)*. ADs are both an expression and a consequence of these advances and conflicts*(2)*.

ADs emerged at the end of the 1960s, in the United States, from an article published by Kutner*(5)*. The discussion involved euthanasia and its legal impossibility. However, the law provided that no patient could be subjected to medical treatment without his consent, and had the right to refuse it, even if it was meant to prolong his life. This would anchor the possibility of refusing treatment in advance, should his medical situation become incurable, thus preventing him from recovering his cognitive capacities. Kutner named "Living will" the document that expresses the advanced wishes of people, capable of doing so, indicating their consent on the extent to which they agree with treatment*(5)*.

In the following decades, ADs developed and consolidated in the United States, mainly through the Patient Self-Determination Act, of 1990*(6)* - and have expanded around the world, becoming one of the emblems of patient autonomy recognition, regarding consent or refusal of treatment in medical care*(3)*. However, after more than 50 years, doubts and criticisms still remain about the nature, design, implementation and effectiveness of ADs. Some of them are: 1st) ADs original defect: assuming the possibility of controlling scenarios in future clinical care according to patient's wishes, is a false promise of ADs*(3,7)* or an act of faith, and not of will*(8)*. What does it mean to control the future?; 2nd) the instability of decisions: patient preferences must be stable in order to be "true" and this is an ambitious idea, because people reflect superficially on their choices before placing them in the "time capsule". Moreover, we have no experience deciding about dying*(9)*. New therapeutic options may change the patient's situation regarding ADs. What does it mean to control the process of dying?; 3rd) the personal identity argument would weaken the patient's moral authority, as the person who drew up his ADs would not be the same in the future, in cases of severe dementia, making their binding nature impossible. After all, should ADs be binding? In this sense, ADs would be ineffective and would promise more than they can deliver *(7,10)*. However, some of these arguments also apply to the informed consent practice in the medical setting, and are indied criticisms to the exercise of personal autonomy.

In Brazil, ADs are recent and still not well-known. They were introduced at the national level after Resolution No. 1,995/2012 of the Federal Council of Medicine*(11)*. In it, ADs are recognised as "the set of wishes, previously and expressly manifested by the patient, on the care and treatment he wants, or does not want, to receive at the moment when he is incapable of expressing, freely and autonomously, his will"*(11)*. Another important recent document has given greater visibility to ADs in Brazil: Resolution No. 41/2018, of the Ministry of Health, "which outlines ADs in the light of integrated continuous palliative care, within the scope of the public Brazilian health system (SUS – Sistema Único de Saúde/Single System of Health)"*(12)*.

Unlike other countries, such as Portugal, the United States, Uruguay, Argentina, Colombia, Spain, France and Italy, Brazil has no law regulating ADs, however, there is the Senate Draft Bill No. 149/2018*(13)* in progress in the National Congress, aiming to regulate them. The present article proposes, 1st) to investigate doubts and criticisms

about ADs, considering that these challenge their moral authority; 2nd) to indicate the repositioning of ADs in the moral field, as stated by Aristotle in *Nicomachean Ethics(14),* on the scope of ethical research; 3rd) to propose this moral field as a starting point for bioethical investigations into their regulation and implementation in Brazil.

Advance directives (ADs): unrealistic expectations and false promises

Original defect: on the impossibility of predicting the future

Since their origin, controversies have surrounded and characterised ADs. One of them was that of predicting and controlling future scenarios in end-of-life medical care. The possibility of controlling scenarios in future clinical care according to patients' wishes has proved to be a false promise of ADs*(7)*. The belief that we can control our future, without knowing the details of our situation, is problematic. What we choose as ends is always, to a greater or lesser degree, limited by the context, in other words, by what our biopsychosocial circumstances allow*(15)*. However, given the impossibility of predicting the future, ADs can be supported by two perspectives: 1) as a precautionary measure; 2) drawn up in the context of Advance Care Planning (ACP)*(4)*. In short: The precautionary principle is adopted when actions must be taken without certainty, but supported by strong evidence of risks that the person wants to avoid; the moral authority of ADs is strengthened under the umbrella of ACP.

Furthermore, ADs are also vague and nebulous: lack of knowledge about future clinical situations prevented precise elaboration of ADs*(4)*, and these generally provided little information about what quality of life meant for patients*(16)*, since the person who wrote their ADs could be in a completely different situation in the future, and the generic nature and hypothetical content of the ADs may not reflect that person's current wishes, values and preferences*(4)*. Indeed, if the specific purpose of ADs is their application in medical care, and they are generic and non-specific in nature, their promises to guide medical practice fail. Moreover, there is a disproportion between precision and prediction about what is determined in these documents as well as the circumstances in which the concrete event takes place*(4)*. Although they are generic in nature and have a hypothetical content, ADs are requested for concrete and specific situations, i.e. they are always requested in the present and this limits their reach considerably*(17)*.

ADs generally fail when trying to determine medical procedures without taking into account the description of applicable scenarios*(18)*. The patient controlling decisions at the end of life is an empty promise of ADs, as they do not take into account the asymmetrical power relationship in the clinical decision-making process. Patients and their families are in a situation of emotional fragility and their surrogate decision-maker will not be in control of the situation as it is the physicians who determine treatment options as well as when ADs will be invoked. In this sense, ADs are empty and do not produce the expected results*(19)*. It should also be noted that it is reasonable to admit the difficulty of thinking about ADs, because there is no reality to support it. The absence of experience about future complications in a person's health makes the process by which one would want to anticipate feelings on the basis of a non-existent reality empty and useless*(20)*. Thus, the argument of medical practice being guided virtually by patient autonomy would not justify the need for ADs*(3)*. This is the reason why some countries made ADs legally binding, so that physicians are compelled to use an AD. Meaning that the burden of proof for its refusal is on the side of the physician that is subject to liability for this practice.

One of the central problems of ADs is the lack of synchrony between the person's early consent or refusal and the physicians' decision and action on necessary treatment. The uncertainties are many in dealing with something that is not currently known*(4)*. What does it mean to express consent about what we do not know? If informed consent is one of the expressions of people's autonomy and self-determination, then ADs do not satisfactorily fulfil what they promise. This is their clearest original defect. We do not control the future. There is always something that escapes us, the circumstances in which our decisions take place. ADs operate in the present time, and as a

tool for future medical care have been shown to be ineffective*(17,18)*. This is also a question regarding the normal practice of informed consent and to avoid this problem there should be a clear and extensive information of the patient/person before writing a living will. However, it should be noted that the patient's legal representative (surrogate decision-maker), as someone who knows the patient's wishes, values and preferences, and the dialogue involving the family in the Advance Care Planning (ACP) process may reduce the ineffectiveness of ADs, when faced with something uncertain. At the end of the next section, we will point out some considerations on ACP.

AD' moral authority and its binding character: the personal identity argument

The moral authority of ADs, its required value, is necessarily associated with their binding character. The wishes, values and preferences of the patient expressed in ADs must be respected in the future, and they must meet at least two criteria: they must not violate the laws of the country, and the person who draws them up must be the same person who will have them respected in the future. One person cannot prepare another person's ADs because this would nullify the expression of the autonomy and self-determination of the person who expresses in advance which medical care is desired or not, in the future*(21,22)*.

Thus, without compliance with these criteria, ADs become useless. Without their binding nature, they become empty. Despite their limited scope in clinical care, as they do not encompass all cases, it is worth considering the performance of ADs in the case of people with severe dementia. If it is correct to state that ADs were created to extend and guarantee people's autonomy in future medical decisions, even when they are no longer autonomous*(3)*, how can we sustain their moral authority? How can we sustain their binding character? If people with severe dementia can have their personal identity altered, then the second criterion is not met, as the person who drew up their ADs is no longer the same person who will have them fulfilled. There is a person prior to cognitive decline and there is another person with severe dementia. But it can also be claimed that it is the same person with profound changes in personality and even in capacity. Meaning that if a person with dementia is incompetent to decide ADs may be clinically useful and legally binding.

The personal identity argument is the strongest criticism of the moral authority of ADs under dementia disorders. It is an old and prevalent criticism*(3,21,23,24)*, and is based on the research of Parfit on psychological continuity, but this will not be addressed here(*25)*. Even though ADs have taken distinctive contours over more than half a century, the personal identity argument is a problem for ADs claims. We will set out this controversy by confronting two rival positions: 1st) the personal identity argument weakens the moral authority of ADs; 2nd) the personal identity argument does not undermine the moral authority of ADs.

The first position is defended by means of three brief considerations *(3,4,24)*:

1.1) Tonelli argues that ADs, for incompetent patients with cognitive decline, have little value because the idea of extending autonomy through them fails. Generally, human beings change their interests throughout life, and with incompetent patients the same thing happens. However, what is lost here is the ability to make decisions, albeit with new values and preferences. He points out further that, claiming that advance decisions about medical care should necessarily be applied even when contrary to the clearest interests of a person who has lost the capacity to make decisions, is a problem, binding that person who drafted their own ADs to this now incompetent person. The illustration he uses is significant: a "pleasantly" mentally ill patient, a mathematician retired due to Alzheimer's disease, expresses his wishes in writing, before the diagnosis, stating that he does not wish to live without his cognitive abilities. Now, faced with his illness, the mathematician seems to carry out his daily activities with satisfaction and responds with a positive sign when asked if he is happy. His interests have inevitably changed, as has his personality, and those who knew him previously find in him only traces of his former self. To fulfil the wishes expressed in the ADs, according to Tonelli, the new person into which the mathematician has become is ignored, and his present interests will be

conditioned to those of a non-existent person*(3)*. However, it can be argued that the meaning of incompetency in decision-making is, precisely, the inability to make choices. So to sustain the first position it must be proved that a patient with advanced dementia has really new values and preferences, because in this case he would have to be considered competent and not incompetent.

1.2) Walsh considers that the moral authority of ADs cannot have a significant influence on medical decisions. The justification starts from two rival positions on the binding character of ADs. The first, a view recognised in philosophical literature, holds that ADs are binding; the second, a widely accepted view in clinical practice, expresses the resistance of physicians to comply with them if they are at odds with the mentally ill patient's current well-being and preferences. Walsh argues that Dworkin's conception, based on the idea that a person's critical interests are stable during their life and that decisions about the end of their life rest exclusively with him, does not justify their strong moral authority. Walsh will defend the second position. There are two reasons: clinical practice at odds with them idea, as noted above, and for disregarding the experiences of cognitive transformations in people with dementia, that imply legitimate changes in their desires, values and preferences. These would be considered to the detriment of those listed in ADs. This would be enough to set back the moral authority of ADs, giving them a weak moral authority, i.e. without the binding character. Walsh cites case study to illustrate these rival positions. Mrs. Black, aged 80, was diagnosed with progressing intermediate dementia. In many situations, she struggled to remember the names and faces of family members. At the old people's home, however, she was recognised by the nurses as a very happy lady, enjoying her daily activities. During this period, Mrs. Black developed a serious bacterial infection. She had an AD which stipulated refusal of medical treatment to prolong her life, if she suffered from an illness that made her incapable of recognising her family members. She would not wish to receive any medical treatment to prolong her life. Her son insisted on compliance with his mother's AD, and soon after she died. The entire medical team was devastated*(24)*. But, again,

1.3) Vergallo pointed out that the generic nature and hypothetical contents of ADs make their binding nature unfeasible, because they do not express, in a specific way, the wishes and preferences of the person. One effect of this is the restriction of their scope. ADs will only be effective in limited clinical situations, such as medical decisions involving patients in a persistent or permanent state of unconsciousness, as well as in patients in a persistent and permanent vegetative state, or with cognitive decline that degenerates decision making skills. Another difficulty that makes the binding nature of ADs unviable is their excessively strict and deterministic application, since they force physicians to comply with the wishes of patients regardless of their content. To reduce the limitations on ADs, increase their effectiveness, and avoid their generic and vague nature, according to Vergallo, it is appropriate to move them to the moment the disease starts, especially dementias, i.e. to move ADs to Advance Care Planning (ACP). Here, there is a certain degree of guarantee in relation to the fulfilment of the patients' wishes already in the context of clinical care, with safer predictions because the patient knows the diagnosis, facilitating the therapeutic relationship. Thus, according to the author, the binding nature of ADs is not sustained if restricted to the generic ADs. When associated with the ACP, their effectiveness will be enhanced*(4)*.

The second position is defended in three considerations*(23,26,27)*:

2.1) For Porteri, the personal identity argument looks attractive from a theoretical perspective, but does not stand the test of reality. In real life, people do not wish to live in the future with dementia. It is not about fear of someone else's future, but their own. It is not the possibility of a new person in the future that terrifies them, personality changes, new desires, values and preferences, but that potential changes are about themselves and not about a new person in the future. Body identity is sufficient for personal identity as it is for psychological continuity. However, there are conflicting interests of patients with severe dementia, the ones from before and after dementia. What mattered before, may not matter after. The way out of this conflict is the prevalence of the patient's critical interests, which are those prior

to their cognitive decline. In this sense, ADs are binding, independent of the 'new preferences', as they give voice to the wishes, values and preferences of people/patients at that present time. They express the way the patients perceive the world and themselves, and are above the preferences and values of physicians and family members. Thus, not fulfilling the ADs of a person with dementia would be the same as never considering them competent and, therefore, unable to decide for themselves about their life*(23)*.

2.2) Jongsma objects to the idea that people with dementia experience cognitive transformation and, therefore, new values, desires and preferences will emerge, in collision with previous ones. The consequence of this, at least, is that the moral authority of ADs is debatable to the extent that previous wishes, values and preferences cannot override current ones - of the person with dementia. For Jongsma, people with dementia progressively lose cognitive capacity, and in their decline are unable to make some decisions for themselves. Behavioural change is not a necessary expression of new preferences and values. It is not plausible that people with cognitive decline would recognize their previous values and preferences, and consider that the current ones should override those. In this sense, ADs have moral authority because people can craft them in such a way as to ensure that their current values, desires and preferences, thoughtfully displayed, may not be possible to live up to as a result of cognitive decline, and they wish these to override future ones arising from dementia. People in this condition progressively lose the capacity to make reasonable choices for themselves. People who design their ADs foreseeing future cognitive decline, and unable to live according to their preferences, attest that they will still be treated according to their carefully thought-out values and preferences, and not according to future values and preferences, a consequence of cognitive decline. Even in the face of uncertainty, of the risks of the decision taken (not remembering previous decisions regarding ADs, and having new preferences and values with cognitive decline), it should not be changed, even in the face of a new situation, such as new preferences and values*(26)*.

2.3) Despite agreeing that changing preferences in progressive dementia may weaken the moral authority of ADs, Menzel considers that this does not destroy them. First, because the expectation of people during progressive dementia to constitute themselves as other selves is irrelevant, as what matters for people who elaborate ADs is not to live too long in a deteriorating way. These patients do not wish to live that way, as an undignified end of life. However, if on the one hand he considers the need for compliance with the ADs of the previously capable person, by their proxies and carers, on the other he recognises the incompetent person is now someone with some value to their own life, finding some subjective value in life. It is, undeniably, a difficult situation, as it maintains a dilemma. Menzel proposes a partial way out: not infrequently, people with severe dementia lack the ability to anticipate tomorrow and remember yesterday. The value of life that remains is that of the moments lived today, just for living them. There is no sense here of the value of people's lives in anticipating tomorrow and remembering yesterday. Still, even if the subjective value for that person whose life is "is not", its value is important. In any case, it considers that the controversy over personal identity does not affect the moral authority of ADs, that is, their binding character*(27)*.

As noted earlier, the personal identity argument seems to be the central philosophical issue about the moral authority of ADs*(21,24,28)*. If incompetent patients change their preferences, wishes and values, as a result of cognitive decline under severe dementia illness, what preferences, wishes and values will be valid? Walsh pointed out the same problem, considering two rival positions, the philosophical one, which logically defends the binding nature of ADs, and clinical practice, which often resists complying with ADs in situations involving dementia*(24)*. The specificity of ADs in the context of people with severe dementia should be emphasised, as patients in this situation may be able to express, in some way, emotions, preferences, wishes and values. However, signs of wellbeing in these patients may not express the realisation of a will to live*(29)*. Thus, which decisions will prevail? Those of the competent person who prepared the ADs, or the decision of the now incompetent patient who ex-

presses other values, wishes and preferences? Moreover, there is another aspect to be considered. If there are two different persons, the one before the illness and the current one, then one of the criteria is not met, in order to guarantee the moral authority of the ADs, which consists in the person who drew them up to be the same person who will have them fulfilled in the future. Such controversies seem to imply a weakening of the moral authority of ADs, since its binding character, which sustains it, is in doubt.

There is, it seems, a dilemma, as both alternatives are unsatisfactory. If ADs are binding on people with dementia, then their moral authority is guaranteed, but it moves away from the proper contexts of clinical care. If, on the other hand, ADs are not binding but indicative, then the moral authority of ADs loses force, and decisions about whether or not to comply with them will bind, more strongly, in the best interests of the patient in the context of the actual circumstances. However, there are also, at least, two possible solutions to this apparent dilemma. A well-known solution is to define through law whether or not ADs, in a given country, are to be legally binding, as is the case in several places, such as the Netherlands, Portugal, Belgium, Denmark and the United States (legally binding) and Germany, Switzerland and Norway (legally non-binding)*(24)*. The other is to face the philosophical difficulties and those of clinical practice that ADs expose.

Some considerations on Advance directives (ADs) and Advance Care Planning (ACP)

ACP is defined as "a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care"*(30:826)*. ACP ideally begins with conversations involving patient, family and the clinical care team about the preferences and objectives of that care*(31)* and medical care no longer focuses on defining specific future treatments, but how different states of health are in accordance with patients' preferences and values*(32)*. The primary idea of ADs, as an event, summarised as the production of a document, is abandoned in order to incorporate the sense of process, as is ACP*(17)*. The shifting of ADs as part of the ACP process redefines their role and mitigates some of the criticisms and doubts about them.

One of the acknowledged advances in this shift is the fact that ACP provides effectiveness to ADs*(33)*, because by starting with the diagnosis of the disease the ACP process will be based on proximate reality, removing the vagueness and generality of ADs*(34)*. Moreover, it does not solely focus on end-of-life care*(31)*.

In any case, part of the criticism and doubts that still persist about ADs can be faced, perhaps, from the delineation of its moral field. To this end, we will resort, in general lines, to aspects of Aristotle's ethical investigation in *Nicomachean Ethics(14).*

The moral field of ADs: resorting to Aristotle's ethical research

Aristotle pointed out, at the beginning of *Nicomachean Ethics*, that the good and just actions, the object of investigation of "political science" (practical sciences - politics and ethics), seem too vague and varied so as to consider their existence by convention rather than by nature*(14:I 31094b-14-17)*. This is due to the consideration that human activities, such as choices and actions, aim at some good (an end) and the ultimate good to which all things tend is *eudaimonia* (happiness, good living, good action), but, about the meaning of *eudaimonia*, there are many conflicting opinions*(14:I 1-2 1094a1-23;4 1095a17-21)*. If wealth and courage are a good, considers Aristotle, there are people who have been lost because of them*(14:I 3 1094b-14-16)*. Ethical enquiry inhabits a grey area because the nature of human actions is essentially uneven. If this is correct, it is not promising to investigate moral questions, such as the meaning of "dignified death" or "dying with dignity," expecting verifiable conclusions.

In this sense, the moral field of the practical 'sciences' - politics, ethics and household administration - has its own identity, and the truth in ethical research is given in general terms*(14:I 3 1094b19-21)*. For Zingano, it is a common understanding that Aristotle recognizes that ethical enquiry supports generalisations of the "all too often" type, but these do not compare to the generalisations of the natural sciences of the "most often" type. The basic register of moral language is particular actions in specific circumstances. In them, human choices and actions operate. Although Aristotle admits strict universalizations, absolute prohibitions, such as not committing murder, these are few*(35)*.

The scope of ethical investigation is that of indeterminacy, according to Aristotle. Therefore, truth in ethics is by approximation, because unlike mathematics, the object of its investigation is human action, and this occurs in circumstances whose moral value is indeterminate. Ethical enquiry (moral reasoning) in Aristotle, does not constitute a prescription of principles and procedures to be followed for right action. The agent is, in a sense, alone in the face of indeterminate circumstances, and it is not possible to assess the moral value of these. Circumstances carry their own moral value and the agent will be faced with them, "here and now", to determine their moral value*(35)*. Similarly, ADs occupy this position of indeterminacy. Although wishes (desires, values and preferences) regarding medical care are expressed in advance for future fulfilment, ADs become effective in the present time, in a concrete and specific situation, and submitted to the clinical context*(32)*.

It seems contradictory to demand from ADs stability in human choices and actions if these always operate in circumstances, in contingency. The moral field is not a field of certainty, of stability. The problem of the inaccuracy of ethics is not only fixed in the limitation of what practical research intends, an approximate truth, but also in the very nature of human actions, unstable and imprecise*(36)*.

Repositioning ADs within the moral field of which Aristotle's ethical investigation recognises and addresses does not diminish their moral authority, it merely establishes their limits and scope in practical situations. These are not only defined according to the nature of ADs, but mainly because it belongs to the practical domain, the moral field, addressed by Aristotle. The unreal and real expectations in relation to ADs depend not only on these, but also on the place it occupies, and this does not seem to be that of the natural sciences, another domain, but the moral field with its specificities and properties. Therefore, the differences between the domains of ethics and another area of knowledge is not one of degree, but of pattern, for these are distinct*(37)*.

There is no reason to condition the effectiveness of ADs solely on scientific demands and decision-making models in end-of-life medical care. They must also be evaluated within their own field, within the practical domain, and survive the scrutiny of clinical contexts, circumstances and contingencies. ADs as a tool to identify treatment preferences in a hypothetical situation, without the concrete disease scenario, are ineffective*(38)*.

ADs are not just a tool to control death and dying, nor are they an expression of our autonomy. It is also about the ontological impossibility of mastering the contingent, uncertain world like ours. Perhaps, because of this, it is not an exaggeration to consider that some of the criticisms to ADs exceed what they can offer, such as not being able to address the instability of human decisions according to hypothetical future scenarios. It is exactly because we do not master the contingent world, even more so the future, that the possibility of choices and actions in the moral sphere are open to us. In a certain sense, the effectiveness of ADs is restricted, paradoxically, to the denial of its binding character, the difficulty of a stability of decisions. Pursuing it, imposes the risk of failure, perhaps the same risk of having to deal, as Wiggins pointed out, with the torments of thought, with the torments of the past, of feelings, and of understanding, which can involve our choices and actions without appeal to normative ethical models*(39)* and, according to Haesen and Shaw, the torments of accepting and facing one's own mortality, not only under the pretext of controlling living conditions, but also of distancing oneself from unrealistic expectations about one's own wishes regarding medical care*(40)*.

Regulation of ADs in Brazil

In Brazil, although applied, ADs are not regulated. Resolution No. 1995/2012 of the Federal Council of Medicine, which provides for ADs, is the reference document for reflections on ADs*(11)*. These were recognised as "a set of wishes, previously and expressly manifested by the patient, on the care and treatment he wants, or does not want, to receive at the moment when he is incapable of expressing, freely and autonomously, his will"*(11:article 1)*. The Resolution defined that physicians and doctors "take into consideration" the patients' ADs or of their legal representative, not attributing them a binding

character. Another Resolution, No. 41/2018, of the Brazilian Ministry of Health, establishes the availability of ADs for patients in Palliative Care throughout Brazil*(12)*. It is the first legislation of the Brazilian executive power on the subject and shows an extraordinary advance in respect to the regulation of ADs in the country, although limited to patients in Palliative Care. In addition to these two resolutions, there is also the Federal Senate Draft Bill No. 149/2018, currently pending in the National Congress*(13)*, aimed at regulating them, and some observations should be made about it.

With regard to draft Bill No. 149/2018, three aspects stand out. 1st) ADs are specifically intended for end-of-life medical care; 2nd) focuses on the preparation of an ADs document to be expressed by means of a public deed; 3rd) contemplates the binding character, but admits exceptions*(13)*. On this third aspect, as pointed out earlier, making ADs binding, or informative, by law does not eliminate the ethical difficulties, especially those directed at people with dementia. Regarding the first and second aspects, conditioning the registration of ADs through public deed and on end-of-life medical care could limit the scope and effectiveness of ADs. The text of the Draft Bill, as it currently stands, may also imprison ADs to one event, that of only drafting a generic and abstract document.

Regarding the knowledge and understanding of ADs in Brazil, studies suggest the existence of the challenge of making, incisively, ADs more known and debated among the population, and among students and health care professionals, as well as the limits of its application*(41-47)*; as to the acceptance of ADs, other studies suggest that they are widely accepted from the moment of their knowledge, both by patients and relatives, as well as by professionals and students in terms of respecting and complying with them*(48-50)*. However, it should be noted that these studies still focus on the knowledge, preparation and fulfilment of ADs, a difficulty to be overcome perhaps over time, as there seems to be an excessive valuing of documents in ADs, or in the determination of models, in detriment of the process involving health care. An indication of this can be found in publications such as those of Dadalto*(51),* Dadalto and Carvalho*(52)*, and Pittelli et al*(53)*.

Difficulties in access to health care and the absence of health literacy among patients, as well as cultural diversity*(34)*, in a country like Brazil, with its continental extension, should be considered when trying to regulate and implement ADs in Brazil. Perhaps the most appropriate way to implement ADs in Brazil is to regulate it by recognising and addressing its limitations and scope. Strategies and documents for its elaboration are important as long as they do not incorporate unrealistic expectations and false promises. The binding or non-binding nature of ADs should be defined in their regulations. As we have noted, ADs lose their identity without their binding nature, but they gain in effectiveness in clinical practice if the circumstances in which they will be fulfilled are recognised. One possible solution is to anchor ADs in the territory of advance care planning (ACP), where patient preferences and values can be recognised and welcomed without much conflict, as they deal with the knowledge of diagnosed illness and not the vagueness and abstraction of future treatments by people who do not live the concrete situation.

Concluding remarks

It is understandable, in some situations, the need for the watchmaker to adjust the clock without stopping it, just as it is reasonable in Brazil to regulate ADs, adjusting them to their current application, considering and recognising its moral field, its limitations and its reach. Its regulation will certainly bring more security to its implementation, but it will not completely keep us away from the doubts and criticisms that still lie on them - philosophical, ethical and bioethical questions.

Thus, the necessary adjustments to the ADs for their implementation in Brazil could perhaps follow this brief outline: 1) ADs do not apply to all cases, as their scope is limited by their moral field; 2) the binding nature of ADs is the clearest expression of their moral authority, but may, as a consequence, be less effective; 3) ADs document models are important tools for knowledge and understanding of the meaning of clinical decisions about the future and not just legally recognized documents; 4) Education on ADs for health care professionals, the population, institutions, among

others, as death and dying are still taboo.

As Aristotle pointed out in *Nicomachean Ethics(14)*, ethical enquiry is that of the practical domain, the realm of the indeterminate, of circumstances, where our choices and actions operate, and truth in ethics is by approximation. In this moral field, perhaps the ADs can be more robust and effective, in the efforts to regulate them in Brazil, when the manifestation provides the person with moral choices and actions that operate in a grey area, allowing healthcare professionals and their representatives to interpret their wishes according to each situation.

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