

The advance directive: benefits, obstacles and limits

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Abstract

The concept of advance directives emerged in response to the technological progress and aggressive medical treatment being employed in ambiguous situations, as in the case of a bad prognosis. The core of this document is the exercise of the patients' autonomy. The Federal Council of Medicine's 1.995/2012 Resolution establishes the criteria for anyone – provided that the patient is legally old enough and fully aware – to be able to choose together with his/her doctor the therapeutic limits at the end of life. The document is optional and may be completed at any time in life and, in the same way it can be modified or cancelled at any time. The purpose of this article is to consider its benefits, obstacles and limits considering the vast amount of researches carried out on this theme and the positive and negative experiences from other countries in order to contribute to the discussion about its effective use in Brazil.

Key words: Advanced directives. Personal autonomy. Bioethics.

Resumo

Diretivas antecipadas de vontade: benefícios, obstáculos e limites

O conceito de diretivas antecipadas de vontade emergiu em resposta ao avanço tecnológico e ao tratamento médico agressivo empregados em situações ambíguas, como no caso de um prognóstico ruim. O cerne do presente documento é o exercício da autonomia do paciente. A Resolução 1.995/12 do Conselho Federal de Medicina estabelece os critérios para que qualquer pessoa – desde que maior de idade e plenamente consciente – possa definir junto ao seu médico quais os limites terapêuticos na fase final de sua vida. O documento é facultativo e poderá ser elaborado em qualquer momento da vida e da mesma maneira modificado ou revogado a qualquer tempo. Este artigo tem por propósito discorrer sobre seus benefícios, obstáculos e limites, considerando o vasto número de pesquisas realizadas sobre o tema e as experiências positivas e negativas de outros países no intuito de contribuir para a discussão de sua efetiva utilização no Brasil.

Palavras-chave: Diretivas antecipadas de vontade. Autonomia pessoal. Bioética.

Resumen

Directivas anticipadas de voluntad: beneficios, obstáculos y limitaciones

El concepto de directivas anticipadas de voluntad surgió en respuesta al avance tecnológico y al tratamiento médico agresivo, utilizándose en situaciones ambiguas, como ante un pronóstico negativo. El núcleo de este documento consiste en el ejercicio de la autonomía del enfermo. La Resolución 1.995/2012 del Consejo Federal de Medicina establece los criterios para que cualquier persona – mayor de edad y plenamente consciente – pueda definir, junto con su médico, los límites terapéuticos en la fase final de su vida. El documento es opcional y puede llevarse a cabo en cualquier momento de la vida y la misma manera modificada o revocada en cualquier forma y tiempo. El propósito de este artículo es discutir los beneficios, obstáculos y las limitaciones considerando la gran cantidad de investigaciones realizada sobre el tema y las experiencias positivas y negativas de otros países, con el fin de aportar a la discusión sobre su utilización de manera efectiva en Brasil.

Palabras-clave: Directivas anticipadas. Autonomía personal. Bioética.

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The Federal Council of Medicine's 1.995/2012 Resolution¹ instigated the Brazilian media on a multifaceted and controversial topic: the Advance Directives, or AD in this present work – also known as living will. In the following month of its publication, pro and con opinions of renowned physicians were reverberating on the pertinence of this resolution².

In force since August 2012, the Resolution establishes the criteria for any person to be able to define with their physician the therapeutic limits at the end of life – provided that the patient is of age and fully aware. The Advance Directives (AD) form is a facultative document and may be prepared modified or revoked any time in life¹.

The Advance Directives concept emerged in response to the technological advance and the aggressive medical treatment used in ambiguous situations, as in the case of bad prognosis. The AD was designed to protect patient's autonomy³, under the belief that, when losing his capacity to choose, through this document he would be more respected in his autonomy as for the desired treatment and/or as for the legal representative that will decide for him in such situation⁴.

In the past 20 years, the Advance Directives were subject of many publications, specially regarding the lack of knowledge about it and its legal validity, which difficults the relations between physician, patient and his family⁵. Notwithstanding the pro and con arguments, several countries have been developing adequate and legal instructions of its use³.

The purpose of this article is to debate on benefits, obstacles and limits of the advance directives in the clinical practice, considering the vast amount of researches on this subject and the positive and negative experiences of other countries in order to contribute in the debate of its effective use in Brazil.

Brief history of the Advance Directives

Just over four decades, the lawyer Luis Kutner has proposed the living will as means of resolving conflicts that arise between patient and physician by the end of patient's life regarding his preferences for certain treatments⁶.

In Medical Subject Headings (according to Bioethics Thesaurus)⁷, "advance directives" are defined as declaration made in advance by the patient, which qualifies for deciding on his care, informing his preferences or authorizing another person to

decide for him. There are essentially two types of advance directives: the first, in which the patient specifies medical treatments that should or not be given in certain situations in the future, also named living will; and the second, Durable Power of Attorney (DPA), which consists in the authorization of another person (a legal representative or attorney) to decide on behalf of the patient in the period when he is able to decide for himself⁸.

The advance directives may be divided into two subgroups: 1) *statement of value*; 2) *instruction directives*. The statement of values describes general preferences and the values of the patient regarding the medical treatment in general, but does not address specific forms of treatment of disease. The instruction directives express the preferences of refusal by certain medical treatments in the context of specific disease⁹.

To promote the use of Advance Directives in the United States (USA), the Congress has approved the Patient Self Determination Act (PSDA), effective from December 1st 1991, emphasizing that all hospitals, long term care facilities, etc. have the obligation to develop written guidelines in relation to them and to educate health professionals about this issue, as well as asking the individual who enters a health care facility if he already has elaborated an Advance Directives or informing about his right to have one¹⁰.

The PSDA was approved in a particular moment of a notorious case of therapeutic obstinacy, known as the "Cruzan case" (the young North American Nancy Cruzan), and court has provided a legal option to facilitate decision making in situations like that. This measure was adopted almost universally by bioethicists, who saw in it an instrument to protect patient's autonomy. It was also accepted by patients, who believed that with this tool they would be free from medical impositions of endless and meaningless treatments; by the physicians, who trusted that with this tool they would be able to meet patient's wishes, what would facilitate decision making in tough situations, and by managers, thinking that it would contribute to reduce costs in health care^{11,12}.

Controversely, critical voices expressed concern¹³⁻¹⁵. The most famous was the letter of 16 ethicists, physicians, nurses, and lawyers, who affirmed that patients would prefer not to talk about death of disability; that they usually do not know how to express their wishes about future; that opinions change and that the legal representative is not always the best translator of the patient's interests¹⁶.

Despite the debate on its effectiveness and the pros and cons of its use, the popularity of Advance Directives has been growing, and in the USA, currently 70% of seniors have formalized their own Advance Directives¹⁷.

In Brazil, the Federal Council of Medicine's 1.995/2012 Resolution proposes the Advance Directives as a voluntary document that may be written anytime in life as well as modified or revoked¹. The document defines the advance directives of will as a *set of desires, previously and expressly manifested by the patient, about the treatment he wants (or does not want) to receive when he is unable to express his will in a free and autonomous manner*¹.

According to the resolution, the AD may be written by the physician in the medical record if authorized by the patient. No signatures are required, neither witness, considering that the physician – because of his profession – has public faith and his actions have legal effect¹. One should note that the resolution points out that the doctor will not take into account the advance directives of will of the patient or representative that, in his analysis, are in disagreement to the precepts given by the Medical Ethical Code¹.

Advance Directives' background

Although the scope of this present work to discuss the moral field that involves the end of life debates, we consider important to succinctly mediate on the emergence of Advance Directives and the debates on its benefits, obstacles and limits.

To humanize death is a basic issue that underlies AD. The commitment to promote the culture of responsibility for the condition of finitude must characterize those who can perceive themselves mortal and does not want to exist upon the denial of this truth¹⁸. Undoubtedly, medicine, the medical culture we have built, is also requested to humanely attend the end of life, not only struggling against death¹⁸.

According to Kóvacs¹⁹, the twentieth century has evidenced a change in the trajectory of death: in the Middle Ages, it was very important to die surrounded by family and the loved ones, discussing about the moribund willings after death, confirming the testament and the distribution of wealth; today it is a taboo.

Each period has as parameter a type of death that seems to be the most desired and each indi-

vidual individualizes how he wants to die¹⁹. When the subject is healthy, however, he does not reflect on its finitude and will only think about this subject when it is unavoidable, usually when affected by a terminal disease. Thus, it is necessary to establish a culture that is able to face the process of dying from a constructive perspective¹⁹.

Marie de Hennezel, in *Intimate Death*, contributes to this construction with a reflection and testimony of her own experience, following for years people who were living their last minutes: *Dying is not, as often judged, a unreasonable time, meaningless (...) the time before death may also be the moment of this person fulfillment and the transformation around him (...) When one is not able to do much, he can still love and feel loved*²⁰.

The scientific and technological advances of diverse areas of knowledge has contributed to stigmatize death, which, far from being seen as natural, becomes classified as the enemy to be defeated at any cost²¹. We cannot deny that these advances, specially in healthcare, have contributed a lot for saving more lives, revolutionizing the quality of life and human longevity; however, *this development could lead to an impasse when regarding the search for cure of to save a life, with every possible effort, in a context of impossible mission: maintaining a life in where death is already present*²². Thus, the counterpart of this current therapeutic obstination deprive many people from a dignified death, considering that we live in a society that denies death.

In the culture we live in, it seems that what does not cure is worthless and the art of caring, that has accompanied health professionals, seems to be abandoned *due to a science that requires accuracy efficiency and results to overcome diseases, an unsuccessful science to face death*¹⁸.

The medical technology instigates important debates in bioethics, once it was in its development that offered the extension and maintainance of life, leading to the dilemma between sacredness of life and the concern of its quality, which consequently leads to the issue of investing in treatments for stopping them²².

We have then all the available resources in medicine to prolong life at the expense of its quality: the *dysthanasia* that, according to Pessine²³ means the excessive extension of death process in patient of futile treatment; in the other hand, the *orthothanasia*, which means the non artificial prolongation of the dying process, besides the natural process²⁴. Therefore, it is important to prioritize the

quality of life remaining and face death as part of a natural process of existence.

The ethical consideration in the dying process assumes the tension between two basic values: the inviolability of human life and the demand of dying with human dignity¹⁸. For Barmejo and Belda¹⁸, the expression dignified death has been criticized and misunderstood for its direct relation to euthanasia, as if it were an open door to think about it. For these authors, however, in their meaning it is not discussed the appreciation of denial of euthanasia.

In this sense, Lepargneur²⁵, in referring that the patient with a disease, terminal or not, has the legal and ethical right to refuse a treatment he considers excessively heavy, emphasizing that *it could avoid confusing the questionable euthanasia with the fair refusal of dysthanasia*. The author cites the affirmation of the Anglican report On Dying Well that *is a mistake to use the word euthanasia for decisions of not preserving life by artificial means, when it would be preferable to let the patient die*.

For Blasco et al.²⁶, in the past years, the concept of dignified death and the recognition of the ethical and deontological obligation of being able to identify when death is inevitable have been strengthening, a moment in where attention must be focused on the monitoring (ACOMPANHAR) of patient and family. In this context of respect for a dignified death, it rises the need for the patient to anticipate and express his will – and this expression to be valid when the individual is no longer in a position to do so²⁶. It does not mean the acceleration of extension of the death process – euthanasia or dysthanasia – and it is up to bioethics to extinguish these questions²². Even because in many countries when the legislation about the AD, the euthanasia is not permitted. That said, one can observe that it is a limitation of the present document.

The Advance Directives help patients to think about illness and death, and lead them to talk with their physician and their loved ones about those questions; it declares how the individual wishes that his process of dying develops and register if they would permit clinical interventions as life support when there are not expectations of recovery. They also notify the desire of receiving care and treatments that will alleviate pain and unpleasant symptoms^{18,27}, stressing that in this process it is important the communication between the parties and that health professionals inform and advise appropriately their patients.

We must, therefore, understand that the Advance Directives should not represent a list of approval or refuse on certain treatments that do not respond to the real needs of a patient²⁷. Although not essential, the individual may also indicate a representative who, if necessary, will take decisions for him, based on the patient's wishes and expectations¹⁸.

Benefits, obstacles and limits

The core of Advance Directives: autonomy

Making decisions considering what is best for a patient when he/she cannot communicate wishes is a usual difficult occurrence for physicians²⁸. The importance of the decision making, informed and shared by the health professional is essential for the quality of care and its outcomes. The literature indicates that patient participation in the treatment leads to better results, which meets the old belief that for the health maintenance of a sick person, the base care is a good and comfortable relation between physician and patient²⁹.

According to Martinez²⁷, the disagreement between health professionals and the patient may extend the medical intervention indefinitely, lengthen life at any cost, provoke moral confusion among professionals, the patient and his family. Thus, facing such possibilities, the advance directives are considered a prominent option to extend the autonomy of a patient in situations where he is unable to exercise it³⁰.

Niebrój³¹ argues that during the 40 years of the history of bioethics and discipline of knowledge, with its own specificity, the debates on autonomy have developed. Initially, the reflection focused on the protection of the patients' rights to participate directly on the decision of the type of care he would get, and the obligation of the physician in revealing information regarding the nature and the consequences of the treatment was emphasized. Nowadays, bioethicists preferably ask how to inform patients in order to ensure that the revealed information will be comprehended by him and, consequently, enable them to consent and authorize the proposed procedure or treatment⁸.

The autonomy in medicine, more reinforced in medical ethics and bioethics, expresses the patient's right to define what is or not a health need. Gracia³² clarifies that this is not the Kantian formal or canonical autonomy, but in a more distinct sense, clearly deontological. In bioethics, autonomy is the expression of a right. Thus, we must accept that

the user is who currently (and certainly in future) defines his health need. It may lead to all sorts of arbitrariness upon the request of less rational demands from the patient, which would tend to lead to frustration and also to discourage the health professional³².

Tonelli³³, in his critical analysis of the Advance Directives, argues that the supposed protection of autonomy is a quite weak claim and that these documents offer only a limited benefit to the clinical practice, once they emerged to ensure control of these decisions to the patient, keeping this autonomy.

However, it should be predicted that the intention of transferring the decision power to the patient or his representative, without considering the adjacent questions related to the clinical practice, would lead to failure³³. Hansot³⁴ argues that, although the intention is not taking off from the patient the decision process, it seems naive that the Advance Directives may change the established social practice in medicine or help the patient to overcome his vulnerability – it would be to expect too much from this document, no matter how prepared it is.

If the Advance Directives reflect the desire of the patient to “control” his own death, it is important to verify if this desire is based in a comprehension about the process of death or to the fear it generates. Likewise, it is also necessary to clarify if the patient is looking for control or compassion, support and comforting presence, given that the negotiation does not deny the patient’s autonomy, but is an enriched perspective of what constitutes an autonomous and authentic action³⁵.

The attractive and the apparent promise of the Advance Directives is that the *enable choice, security and control over death: the ultimate exercise of autonomy*³⁵. They assume that the preferences regarding care are easily identified by patients and kept by physicians³⁶, but this conception does not consider the uncertainties of most clinical situations and even less the subtle influences of power help by those who determine what options will be offered.

Considering that and according to Gilligan and Rafin³⁶, it can be said that these expectations of choice, security and control are misplaced, and to propose the AD to have a more limited role, although not losing its vital need to promote the negotiation process needed for the end of life.

The questionable stability of decisions

It seems logical that decisions made based in the knowledge and the evaluation of medical

data, in the prognosis of the disease and the objectives that must be negotiated between patient and health professionals, and not under the influence of infirmity, fear and pain²⁷. Forcing patients to decide on which treatments they want or not to receive in these circumstances or to nominate a legal representative to make it for him may be legally acceptable, but it is at least ethically problematic²⁷.

An urgent ethical problem in the use of AD is that competent people may not always be capable to make decisions about their future when unexpectedly face their “disabled selves”³⁰; in consequence, there is a concern regarding the authentic and stability of the decision, given that in the elaboration of the document, the patient bases himself on an imaginary reconstruction of how his life would be in a certain condition never experienced before. This reconstruction is highly problematic due to the difficulty of predicting future facts. Given the difficulty on decision making on health issues, specially with regard to the advance directives, all the underlying uncertainty must be considered on this hypothetical future³⁷.

In a research made by Schiff et al.²⁸, that had as one of its objectives to determine the experiences and opinions of geriatricians on the AD, it was identified within the concerns about its use the possibility of changing the feelings when the situation that was only expected before is now experienced, and considered disturbing the fact that the document is filled by someone with no comprehension of the decisions or how influence he/she can be by other people.

Several studies have attempted to address the question about such persistence, and have verified high levels of stability in decisions related to the preference for treatments in hypothetical scenarios over a period of up to three years, both for inpatients³⁸ and outpatients³⁹ and in long stay institutions⁴⁰. The results of this research made by Schiff et al.²⁸ show that, from the sample of 1426 geriatricians, 842 have replied to the questionnaire and many had a positive experience taking care of patients who had AD. Despite acknowledging the existence of problems, many of those physicians supported the use of this document of the elderly.

The main positive effects from the AD relate to the fulfillment of the patient’s will for treatments less invasive, predominantly palliative at the end of life; to the facilitation of discussions about the end of life; to the help on reaching a consensus and providing clarity for the other members of a multidisciplinary team and relatives regarding the care²⁸. According to Schiff et al.²⁸, few negative effects were described,

among them the fact that there are situations in where the care had to be transferred to another medical team due to conflicts in the convictions of professionals and what was expressed in the AD.

Literature is confusing when related to the effectiveness of these documents. Older studies have revealed that they had a minimal effect on the decisions to hamper or remove care⁴¹⁻⁴⁵ and had a little contribution to increase the consistency of the care given and the desire of a patient⁴⁶. A more recent study showed that AD patients are less likely to receive life-sustaining treatments or to die in a hospital⁴⁷, but there is still no certainty if results are consistent with the desires of patients. A prospective study has concluded that the previously expressed desires were followed by 75% of cases, independently of the existence of Advance Directives⁴⁶. Data on the effectiveness of using a legal representative through procurator to decide on health care are limited.

Studies related to the opinion change of a person when facing the situation previously planned are rare due to the difficulty in accomplishing them. The research with retired physicians who presented functional decline and/or worsening of depression suggests that they preferred aggressive treatments of life support, compared to those in similar age who did not present the functional decline⁴⁸. Schiff et al.²⁸ have not found any longitudinal study of treatment preference before and after a relevant change in health and, therefore, suggest that a practical approach for this uncertainty is that doctors initiate a regular revision of the document, particularly when a change in the health status happens.

Another relevant aspect to be considered in the filling of the AD were considered in the study made by Silveira et al.⁴, who has investigated the prevalence and predictors of the capacity loss for decision making and the decision-making by the end of life, as well as the association between AD and the care received, including the correlation between the preferences registered and the type of decision of the legal representative taken by the end of life.

The research was conducted by interviews with legal representatives of individuals who were 60 years old or older that have passed away and that participated on the cohort study entitled Health and retirement study. The interviews were made up to 24 months after the patient's death. From the 3746 subjects presented by those interviewed, 42.5% required decision making, among which 70.3% had lost their capacity of deciding and 67.6% had signed an AD. This result shows the significant increase in

the use of AD since the study made to understand the prognostic and preferences for results and risks of treatment (Support), made in 1996⁴⁹, which reported that only 21% of seriously ill and hospitalized patients had the Advance Directories.

The subjects who had an AD were more inclined to opt for limited care (92.7%) or comfort care (96.2%), rather than all possible care (1.9%); 83.2% of subjects who requested limited care and 97.1% of the ones who requested comfort care received it according to their own preferences⁴.

The study also shows that few subjects preferred aggressive care, but half of them did not receive it. The authors argue that some people may conclude that this finding indicates that the ADs are used to disown the opted health care, but it would be a misinterpretation of data, once the statistical regression analysis demonstrated that the preference for aggressive treatment significantly increased the probability of receiving such care when compared to someone who did not request it. What then can explain this result?

First, the aggressive treatment perhaps was not the best option for the patient, despite the desire to receive it. Second, among the subjects that required that type of care, most had nominated a legal representative to decide for them, which often overrides the wishes of patients - usually because the circumstances required it to be done.

The authors suggest a more favorable interpretation of these data, that is, that the AD has an important effect on the care received and that the nomination of a legal representative for decision making about health care is needed in case of unexpected factors. Silveira et al.⁴ argue that if we accept that the nomination of a legal representative is an extension of the patient's autonomy, then we also have to accept his/her decision, even when contrary to the patient's wish, is based on what is best for the patient. For more patients to benefit from these valuable tools, the authors conclude that the system should ensure the health care providers time, space and remuneration to lead these debates, which take time and are necessary for planning appropriately the care at end of life⁴.

The ambiguous terminology used in AD

Another contentious point about the AD is pointed by Stone⁵⁰, whose article scrutinizes the terms used in it, observing the difficulty in defining them to be equally understood by all. The author reports that many ADs do not have the definition

or meaning of the terms used in its description and warns that with no definition of the term "terminal illness" in the document itself, most patients will only vaguely understand the circumstances in which it applies - but will probably not even realize that they ignore this determining fact.

The author describes that in his experience as physician, the relatives and the clergy, with whom the patient probably will discuss the document, will not have a better understanding of what the term means, being that the majority of people who will sign the document does not know that there is a problem. The word "terminal", for example, is considerably vague and may comprise a wide range of situations. The author reports witnessing people die in the mechanical ventilator against their will, due to how elusive the term is⁵⁰.

Stone⁵⁰ also emphasizes to the notion of life support treatments that only help on delaying the dying process and argues that it makes no sense. The author points that, in general, signing an AD does not preserve the autonomy of a patient; instead, puts him at the mercy of a physician, who decides whether the patient is competent to participate on decisions about his own treatment, how long is considered a relative short time, and who defines which life support treatments are inevitable. Thus, explains the author, if the patient is in a condition that will, sooner or later, lead to death, and the physician responsible for the treatment believe that it is not worth preserving the patient's life, then the patient has a "terminal illness" and any medical intervention that could prolong his life, including antibiotics, dialysis and artificial hydration, is considered a "life-sustaining treatment". If the patient is in the same condition, but the physician responsible for his treatment believes that it is worth preserving the patient's life, then interventions that lengthen the patient's life are not considered "life-sustaining treatments" and the patient is not in a "terminal phase".

Given this perspective is it relevant the observation made by Martinez²⁷ on the fact that a poorly drafted or misinterpreted AD can add an extra layer to an already technical and complicated process of decision making; it can be used as a tool to reduce the responsibility of professionals and health institutions, as well as contributing for them to escape from the responsibility of worrying about their patients. The author also argues that although the AD has emerged to permanently improve communication between physician and patient, by basing themselves in a standard or general rule, physicians may use it to easily separate themselves from the

concern about a particular situation of the patient and simply abandon him¹⁸.

By filling out this document we cannot be yield to ourselves; autonomy as solitude is not ethical, that is, the patient wants to be genuinely respected, but it does not mean to abandon him to his own luck without the due care and help - attitudes capable of benefiting him in that specific condition. The greatest risk of health care in the twenty-first century is not the physician's autocratic paternalism, but the respectful abandonment of the patient²⁷.

Besides, the right to participate on decision-making processes affecting their own lives should comprise all human beings, since the patient is endowed with dignity and should be respected and recognized as a moral agent³². However, observes Stone⁵⁰, despite recognizing our duty of respecting all human beings, we do not know how to perform it. Fagerlin and Schneider⁵¹ argue that to be qualified for filling out the AD, the individual must not only have the adequate information on the nature of disease and its treatments (medical knowledge), but also seek to understand the unforeseen circumstances that will influence future treatments and the preferences of the patient (prophetic knowledge). Niebrój³¹, however, considers that the unpredictability constitutes essential and inevitable element of human / social life.

Given these considerations, the challenge is to design advance directives that could consider the possibility of change in patient's answers - and one possibility would be to frequently review the document with the patient, when his disease worsens. Nevertheless, determining the frequency, or the event or indicator for returning to this discussion, is not a simple task⁵².

Another approach is based on the distinction proposed by Fins et al.⁵³, entitled contract versus pact, in which the planning process of anticipated care reveals itself differentiated. Some individuals hope that their wishes are carried out exactly as specified (in the contract); others, to have their essential values understood and put into practice, need to be verified whether the action (treatment / procedure to be performed) contradicts or not the statement or preference expressed in his AD (pact). Clearly, says Schwatz⁵⁴, for the purpose of care planning, the health professional may need to know in advance the preferences of patients and their representatives, either for the contract or pact, and in what they agree on. Moreover, it would be helpful to know if, in general, the preferences expressed by contract or pact consider the probability of changing

some aspects regarding the treatment for life support, in case the advanced disease is more tolerating than it was expected to be⁵⁵.

Alternative approaches

In this multifaceted context highlights the approach named Advanced Care Planning (ACP), which redirects the focus of a patient simply express preference or refusal of certain interventions such as dialysis, mechanical ventilation, tube feeding and hydration, to the objectives of care. Messinger-Rapport, Baum and Smith⁵⁶ defend the nomination of a *proxy* or *legal representative*, as the procurator for medical decisions is more flexible and broadly applied than the living will. The authors argue that approaching the patient by offering a list of life-sustaining treatments before discussing the goals of the care and the prognosis is the same as putting the cart before the horse, and threatens to take away the focus from the need of inquiring about the values and to offer the appropriate care⁵⁶.

According to Pearlman et al.⁵⁷, in the AD approach, individuals formulate their own preferences based on considerations of life quality in their current condition and/or in a predictable health situation (as an example the terminal illness) and the benefits as well as the overweight of life-supporting treatments. These values and preferences are then communicated to close relatives or potential representatives, who will make the decisions for the patient and for the health provider team. The last step is to document these values and preferences by the advance directives. The authors recognize the existence of barriers regarding the AD due to the social reluctance of thinking about death⁵⁷.

None of the interventions made to solve these barriers ensures a wide AD or improves the most important result, which is the comprehension of the patient's values and wishes by health care providers or the person nominated to make the decision for him⁵⁷. Pearlman et al.⁵⁷ observe that the AD may not be appropriate to everyone; therefore, physicians should efficiently target patients who could benefit from this document, that is, those at risk of losing the ability to make decisions (for example patients with dementia, terminal illness, fragility or with stroke history in the family) and those who are far from or do not have household.

In this sense, Hawkins et al.⁵⁸ have highlighted the increased number of evidences suggesting that patients do not want to actually exercise this kind of control over decisions related to end of life, even

though the AD forms are increasingly detailed to safeguard a higher autonomy of the subject. The authors state that, in recent years, a greater attention has been given to AD oriented towards values and for those who consider the importance of family ties in the planning related to end of life care. The authors conducted a study that proposed to examine the attitudes of patients and their legal representatives regarding the use of AD for the management of end of life treatments. Three hundred and thirty seven elderly aged over 65 years who participated in another longitudinal study about AD and their substitutes were interviewed. The results revealed that few individuals wished to register their preferences for specific medical treatments and demand that they would be followed, *ipsis litteris*, close by the period of death.

The desire of most interviewees was to express general preferences, such as values and goals of care, in addition to/or instead of preferences for specific medical treatments, and also allow certain freedom to the legal representative in the process of decision making⁵⁸. That is, patients were more interested in transmitting their values and goals of care than in specifying treatments and interventions. More than half said that it was definitely necessary to register their wishes in the AD. However, the authors note that the format of most of these documents does not reflect this priority and warn about the importance of healthcare professionals and healthcare providers, as well as researchers and public policy representatives, to recognize this possibility.

Final Considerations

This information report many benefits, obstacles and limits of using the AD, but despite all its difficulties everything leads to the increase of its use, which makes the focus of this debate to move toward its more effective use. Under an optimistic perspective, it can be said that there is an intersection point between the pros and cons arguments, that is, that these documents shall integrate a process that fosters an open dialogue between families, physicians, and the patient, reflecting real needs, beliefs, values, goals of care, and patient preferences.

That said, and despite the CFM 1995/12 Resolution formulated more than 40 years after the emergence of living will, it highlights the importance that Brazil is able to learn from the experiences of other countries to ensure a legislation that encourages positive and well informed relationships be-

tween medical staff and patients about their preferences for care at the end of life. In this process, it is important the limitations of AD to be recognized and understood so that they can actually contribute to the quality of care given at the end of life, and that are in fact used towards patient's autonomy when in the process of death.

For this to happen we conclude the urgency of studies in Brazil which will enlighten and clarify the various aspects of this complex subject, contributing to a broader proposal of establishing a culture that can face the process of death and dying in a more constructive manner, and that dignified death may represent not only a concept, but reality.

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References

1. Conselho Federal de Medicina. Resolução CFM nº 1.995, de 31 de agosto de 2012. Dispõe sobre as diretivas antecipadas de vontade dos pacientes. [Internet]. 2012 (acesso 5 jan. 2013). Disponível: http://www.portalmédico.org.br/resolucoes/CFM/2012/1995_2012.pdf
2. Lopes AD, Cuminale N. O direito de escolher. Revista Veja. São Paulo: Editora Abril; 2012. Ano 45, nº 37. p. 98-106.
3. Brown BA. The history of advance directives: a literature review. J Gerontol Nurs. 2003;29(9):4-14.
4. Silveira MJ, Kim SYH, Kenneth M, Langa MK. Advance directives and outcomes of surrogate decision making before death. N Engl J Med. 2010;362:1.211-8.
5. Ashby M, Wakefield M, Beilby J. General practitioners' knowledge and use of living wills. BMJ. 1995;310(6.974):230.
6. Fuchs VR. The growing demand for medical care. N Engl J Med. 1968;279(4):190-5.
7. National Library of Medicine. Advance directives. 1991 (acesso 10 dez. 2012). Disponível: <http://www.ncbi.nlm.nih.gov/mesh/?term=advance+directives>
8. Beauchamp TL, Childress JF. Principles of biomedical ethics. 4ª ed. New York: Oxford University Press; 1994.
9. Toller CA, Budge MM. Compliance with and understanding of advance directives among trainee doctors in the United Kingdom. J Palliat Care. 2006;22(3):141-6.
10. Bogardus ST, Bradley EH, Williams CS, Maciejewski PK, van Doorn C, Inouye SK. Goals for the care of frail older adults: do caregivers and clinicians agree? Am J Med. 2001;110(2):97-102.
11. Greco PJ, Schulman KA, Lavizzo-Mourey R, Hansen-Flaschen J. The patient self-determination act and the future of advance directives. Ann Intern Med. 1991;115(8):639-43.
12. Singer PA, Siegler M. Advancing the cause of advance directives. Arch Intern Med. 1992;152(1):22-4.
13. Emanuel LL, Barry MJ, Stoeckle JD, Ettelson LM, Emanuel EJ. Advance directives for medical care: a case for greater use. N Engl J Med. 1991;324(13):889-95.
14. Emanuel LL, Emanuel EJ. The medical directive: a new comprehensive advance care document. Jama. 1989;261(22):3.288-93.
15. Kelner MJ, Bourgeault IL. Patient control over dying: responses of health care professionals. Soc Sci Med. 1993;36(6):757-65.
16. Lo B, McLeod GA, Saika G. Patient attitudes to discussing life-sustaining treatment. Arch Intern Med. 1986;146(8):1.613-5.
17. Teno JM, Gruneir A, Schwartz Z, Nanda A, Wetle T. Association between advance directives and quality of end-of-life care: a national study. J Am Geriatr Soc. 2007;55(2):189-94.
18. Bermejo JC, Belda RM. Testamento vital: diálogo sobre la vida, la muerte y la libertad. Madrid: PPC Editorial; 2011.
19. Kovács MJ. Autonomia e o direito de morrer com dignidade. Bioética. 1998;6(1):61-9.
20. Hennezel M. A morte íntima. 2ª ed. São Paulo: Ideias e Letras; 2004.
21. Esslinger I. O paciente, a equipe de saúde e o cuidador: de quem é a vida, afinal? Um estudo acerca do morrer com dignidade. In: Pessini L, Bertachini L, organizadores. Humanização e cuidados paliativos. São Paulo: Loyola/Centro Universitário São Camilo; 2004.
22. Kovács MJ. Bioética nas questões da vida e da morte. [Internet]. Psicol USP. 2003 (acesso 13 dez. 2013);14(2):115-7. Disponível: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0103-65642003000200008
23. Pessini L. Distanásia: até quando prolongar a vida? São Paulo: Centro Universitário São Camilo/Loyola; 2001.
24. Junges JR, Cremonese C, Oliveira EA, Souza LL, Backes V. Reflexões legais e éticas sobre o final da vida: uma discussão sobre a ortotanásia. [Internet]. Rev. bioét. (Impr.). 2010 (acesso 20 jun. 2014);18(2):275-88. Disponível: http://revistabioetica.cfm.org.br/index.php/revista_bioetica/article/view/564/537

25. Lépargneur H. Bioética da eutanásia: argumentos éticos em torno da eutanásia. [Internet]. Bioética. 1999 (acesso 19 jun. 2014);7(9):41-8. Disponível: http://revistabioetica.cfm.org.br/index.php/revista_bioetica/article/view/292/431
26. Blasco AC, Montfort FC, Palomar RM. Conocimientos y actitudes de los profesionales de los equipos de atención primaria sobre el documento de voluntades anticipadas. *Aten Prim*. 2010;42(9):463-9.
27. Martínez K. Los documentos de voluntades anticipadas. *Anales Sis San Navarra*. 2007;30(3 Suppl):87-102.
28. Schiff R, Sacares P, Snook J, Rajkumar C, Bulpitt CJ. Living wills and the mental capacity act: a postal questionnaire survey of UK geriatricians. *Age Ageing*. 2006;35(2):116-21.
29. Balint JA. Brief encounters: speaking with patients. *Ann Intern Med*. 1999;131(3):231-4.
30. Fazel S, Hope T, Jacoby R. Assessment of competence advance directives: validation of a patient centred approach. *BMJ*. 1999;318(7182):493-7.
31. Niebrój LT. Advance directives and the concept of competence: are they a moral barrier to resuscitation? *J Physiol Pharmacol*. 2007;(5 Suppl):477-84.
32. Gracia D. Pensar a bioética: metas e desafios. São Paulo: Loyola; 2012.
33. Tonelli MR. Pulling the plug on living wills: a critical analysis of advance directives. *Chest*. 1996;110(3):816-22.
34. Hansot E. A letter from a patient's daughter. *Ann Intern Med*. 1996;125(2):149-51.
35. Drought TS, Koenig BA, Raffin TA. Advance directives: changing our expectations. *Chest*. 1996;110(3):589-91.
36. Gilligan T, Raffin TA. Whose death is it, anyway? *Ann Intern Med*. 1996;125(2):137-41.
37. Tulskey JA, Chesney MA, Lo B. How do medical residents discuss resuscitation with patients? *J Gen Intern Med*. 1995;10(8):436-42.
38. Patrick DL, Pearlman RA, Starks HE, Cain KC, Cole WG, Uhlmann RF. Validation of preferences for life-sustaining treatment: implications for advance care planning. *Ann Intern Med*. 1997;127(7):509-17.
39. Emanuel LL, Emanuel EJ, Stoeckle JD, Hummel LR, Barry MJ. Advance directives: stability of patients' treatment choices. *Arch Intern Med*. 1994;154(2):209-17.
40. Bosshard G, Wettstein A, Bar W. How stable is the attitude of aged people towards life-extending measures? Results of a 3-year follow-up in nursing home residents. *Z Gerontol Geriatr*. 2003;36(2):124-9.
41. Smedira NG, Evans BH, Grais LS, Cohen NH, Lo B, Cooke M *et al*. Withholding and withdrawal of life support from the critically ill. *N Engl J Med*. 1990;322(5):309-15.
42. Schneiderman LJ, Kronick R, Kaplan RM, Anderson JP, Langer RD. Effects of offering advance directives on medical treatments and costs. *Ann Intern Med*. 1992;117(7):599-606.
43. Teno JM, Lynn J, Phillips RS, Murphy D, Youngner SJ, Bellamy P *et al*. Do formal advance directives affect resuscitation decisions and the use of resources for seriously ill patients? *J Clin Ethics*. 1994;5(1):23-30.
44. Lo B, Saika G, Strull W, Thomas E, Showstack J. 'Do not resuscitate' decisions: a prospective study at three teaching hospitals. *Arch Intern Med*. 1985;145(6):1.115-7.
45. Goodman MD, Tarnoff M, Slotman GJ. Effect of advance directives on the management of elderly critically ill patients. *Crit Care Med*. 1998;26(4):701-4.
46. Danis M, Southerland LI, Garrett JM, Smith JL, Hielema F, Pickard CG *et al*. A prospective study of advance directives for life sustaining care. *N Engl J Med*. 1991;324(13):882-8.
47. Degenholtz HB, Rhee YJ, Arnold RM. Brief communication: the relationship between having a living will and dying in place. *Ann Intern Med*. 2004;141(2):113-7.
48. Straton JB, Wang NY, Meoni LA, Ford DE, Klag MJ, Casarett D *et al*. Physical functioning, depression, and preferences for treatment at the end of life: the Johns Hopkins precursors study. *J Am Geriatr Soc*. 2004;52(4):577-82.
49. Pritchard RS, Fisher ES, Teno JM, Sharp SM, Reding DJ, Knaus WA *et al*. Influence of patient preferences and local health system characteristics on the place of death. *J Am Geriatr Soc*. 1998;46(10):1.242-50.
50. Stone J. Advance directives, autonomy and unintended death. *Bioethics*. 1994;8(3):223-46.
51. Fagerlin A, Schneider CE. Enough: the failure of the living will. *Hastings Cent Rep*. 2004;34(2):30-42.
52. Das AK, Mulley GP. The value of an ethics history? *J R Soc Med*. 2005;98(6):262-6.
53. Fins JJ, Maltby BS, Friedmann E, Greene MG, Norris K, Adelman R *et al*. Contracts, covenants and advance care planning: an empirical study of the moral obligations of patient and proxy. *J Pain Symptom Manage*. 2005;29(1):55-68.
54. Schwartz C. Decision making at the end of life: shifting sands. *J R Soc Med*. 2005;98(7):297-8.
55. Schwartz CE, Wheeler HB, Hammes B, Basque N, Edmunds J, Reed G *et al*. Early intervention in planning end-of-life care with ambulatory geriatric patients: results of a pilot trial. *Arch Intern Med*. 2002;162(14):1.611-8.
56. Messinger-Rapport BJ, Baum EE, Smith ML. Advance care planning: beyond the living will. *Cleve Clinic J Med*. 2009;76(5):276-85.

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57. Pearlman R, Starks H, Cain KC, Cole WG. Improvements in advance care planning in the veterans affairs system: results of a multifaceted intervention. *Arch Intern Med.* 2005;165(6):667-74.
58. Hawkins NA, Ditto PH, Danks JH, Smucker WD. Micromanaging death: process preferences, values, and goals in end-of-life medical decision making. *Gerontologist.* 2005;45(1):107-17.

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