Advanced directive: a Brazilian model

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Abstract

This article is the result of the doctoral thesis, whose general objective was to propose a model of advance directives to Brazil. Therefore, we carried out a literature review on advance directives in America and Europe, especially in the United States and Spain, and semi-structured interviews with medical oncologists, intensivists and geriatricians in Belo Horizonte-MG. It was realized that the Brazilian model should distance itself from form models used in many American states and provinces in Spain, in order to leave room for the subjectivity of each patient. We conclude, therefore, that the proposed model has the capacity to assist citizens who want to advance their policy, as well as doctors who wish to provide this option for their patients, but it should always be used as a guide and not as a closed model to the peculiarities of each situation.

Key words: Right to die. Advance directives. Personal autonomy.

Resumo

Diretivas antecipadas de vontade: um modelo brasileiro

O presente artigo é fruto de tese cujo objetivo geral foi propor um modelo de diretivas antecipadas de vontade para o Brasil. Para tanto, realizou-se uma revisão de literatura sobre as diretivas antecipadas nas Américas e na Europa, especialmente nos Estados Unidos da América e na Espanha, e entrevistas semiestruturadas com médicos oncologistas, intensivistas e geriatras de Belo Horizonte-MG. Percebeu-se que o modelo brasileiro deve se distanciar dos padrões de formulários utilizados em muitos estados norte-americanos e províncias espanholas, visando deixar espaço para a subjetividade de cada paciente. Conclui-se, assim, que o modelo proposto tem o condão de auxiliar o cidadão que deseja fazer sua diretiva antecipada, bem como os médicos que desejam apresentar essa possibilidade para seus pacientes, mas deve ser sempre utilizado como guia e não como um modelo fechado às peculiaridades de cada situação concreta.

Palavras-chave: Direito a morrer. Diretivas antecipadas de vontade. Autonomia pessoal.

Resumen

Directivas anticipadas: un modelo brasileño

Este artículo es el resultado de la tesis doctoral, cuyo objetivo general fue proponer un modelo de directivas anticipadas de voluntad para Brasil. Por lo tanto, se realizó una revisión bibliográfica sobre las directivas anticipadas en las Américas y en Europa, especialmente en Estados Unidos y España, y las entrevistas semiestructuradas con los médicos oncólogos, intensivistas y geriatras de Belo Horizonte-MG. Se ha percibido que un modelo brasileño debe alejarse de los modelos de formularios utilizados en muchos estados norteamericanos y provincias de España, con el fin de dejar espacio para la subjetividad de cada paciente. Se concluye, por tanto, que el modelo propuesto tiene la capacidad de ayudar a los ciudadanos que desean hacer su directiva anticipada, así como los médicos que desean ofrecer esta opción a sus pacientes, pero siempre debe ser utilizado como una guía y no como un modelo cerrado a las peculiaridades de cada situación concreta.

Palabras-clave: Derecho a morir. Directivas anticipadas. Autonomía personal.

Research article

Approval CEP/UFMG 128.454

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The authors declare no conflict of interest.

Advance directives of will (ADW) are a genre of expression of intention for medical treatment, whose species are the living will and enduring mandate.

The living will has its origin in the United States of America (USA), precisely in 1969, when Luis Kutner proposed the adoption of the *living will,* also known in Brazil as living wills – document that would serve to protect the *individual right to allow death* [1]. In other words, living wills proposed by Kutner proceeded on the assumption that the patient has the right to refuse to undergo medical treatment whose purpose is strictly to prolong his life, when his condition is irreversible or when he is in a vegetative state with no chance of regaining his faculties, currently known as persistent vegetative state (PVS) [2].

In 1991, the U.S. Congress passed the Patient Self-Determination Act [3], a federal law recognizing the patient's right to self-determination. In the mid-90s, all the U.S. states had expressly recognized the legality of these documents. In this period, there were two types of advance directives: *living will* and *durable power of attorney for health care* (DPAHC). While *living will* consisted of the document by which the individual expressed the refusal of treatment faced with a diagnosis of terminal illness or proof of PVS, the DPAHC, translated as enduring mandate, consisted in the appointment of a person to make decisions regarding medical treatment when the individual himself was no longer able to do so – discapacity could be permanent or temporary.

Despite the advancement of these documents on the right to self-determination of the individual authors such as Brown [4] state that no more than 25% of the U.S. population have *living will,* which is why Fargelin and Schneider [5] enacted the institute bankrupted, citing as causes the lack of interaction between doctor and patient, the impossibility to predict what would be the patients' will before a fatal diagnosis, the difficulty of individuals to transfer their wishes into a document, the use of generic terms and the cost of completion of the document, among others. The low compliance to the *living will,* combined with the document's criticism and increased patient autonomy, has paved the way for new genres of expression of intention documents for medical treatment in the U.S..

While that country's advance directives are being improved and new documents of expression of intention for medical treatment are being implemented, the situation in Europe and Latin America is still of implementation of that institute. In Europe, the discussion took shape with the *Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine,* also known as *Convention on Human Rights and Biomedicine* or *Convention of Oviedo* [6], ratified by Portugal , Spain and Switzerland, among others. After this agreement, countries such as Spain[7,8] and Portugal [9] legislated on the subject.

In Latin America, Puerto Rico [10] was the first country to legislate on ADW, and more recently, Argentina and Uruguay [11,12] did the same. Although Brazil has not yet legislated on the subject, on August 31, 2012 the Federal Council of Medicine (CFM, Portuguese for Federal Council of Medicine) adopted Resolution CFM 1.995 [13], recognizing a patient's right to express their will about medical treatments and appoint representatives for this purpose, and the duty of the doctor to fulfill the patient's will.

This resolution helped to warm the debate particularly on the need for legislative regulation on advance directives. This is because, as an organ of class, the resolution has legal force only among physicians, not having the power to regulate essential aspects of the subject as the formalization, the content, the capacity of the grantors, the expiry date and the creation of a national registry. However, the class character of the resolution does not withdraw its merit, on the contrary, it turns the eyes of society back to the discussion of this matter of paramount importance, especially because many Brazilian citizens have already searched notary offices aimed at registering their advance directives, indicating that the subject has social importance to justify the debate.

Method

The study has adopted a qualitative research as it *seeks to describe and understand a phenomenon, and not explain it or make predictions* [14]. The overall objective of the research is to propose a model of ADW, in light of the Code of Medical Ethics, adequate to the Brazilian reality. Thus, it was made a literature review and a documentary survey of models of ADW in each one of the U.S. states and in each one of the Spanish autonomous communities.

It was also conducted a qualitative field research, using semi-structured interviews applied to intensive care physicians, oncologists and geriatricians in the city of Belo Horizonte, who were registered at the Regional Medical Council of the State of Minas Gerais website, chosen at random. It was not set, a priori, the number of interviews, as it was used the saturation tool, which is used when *there is*

the perception that the new data to be collected decant themselves, i.e. are not diluted or absorbed in theoretical formulation which is being processed, no longer contributing to its consolidation [15]. Thus, the interviews stopped when it was realized redundancy of information.

The invitation of the interviews was done by phone or *e-mail,* according to the ease of contact with the interviewers. The interviews were recorded and held at venues chosen by respondents, either at their offices or residences and had a maximum duration of thirty minutes, always initiated with the presentation, reading and signing of the consent form. Over six months the researcher made contact with nine physicians who met the inclusion criteria, five of whom agreed to participate. Of these five, two were intensivists, two oncologists, and one geriatrician. Only the geriatrician was female. Coincidentally, all the subjects were over 10 years of medical education. It ended up not being necessary to adopt any more interviews, due to the saturation criterion consistent in the responses of five of the respondents.

The research was based on the following questions: "What is your opinion on the suspension of nutrition and hydration in cases of persistent vegetative state"; "What types of treatment/procedures do you accept the patient to refuse undergoing?"; "How do you think the doctor should contribute to the making of living wills?"; "In which medical conditions can you think of the suspension of procedures?"; and "How do you face a situation in which there is a conflict between the will of the patient and family wishes concerning the treatment to be done?".

After each interview the audio was transcribed and recordings will be maintained until the publication of the results. The transcript was followed by reading the interviews in conjunction with listening to the recordings three times, at least to ensure the reliability of transcription. Subsequently, a superficial reading of the material was taken, attempting to understand the overall direction and general argument of each interview, to separate the key arguments and cross-reading. This process was executed to carry out the structural decoding, in order to *check the specific structuring, personal dynamics, that behind the torrent of words, rules the mental process of the respondent* [16]. Thus, the core ideas of the arguments of each research subject were grouped, coded and categorized for later being compared with others, allowing the construction of themes panels.

That done, we moved to close the analysis, comparing the different arguments found with the concepts of argumentative analysis, with the position of literature on the topic and models of ADW from the U.S. states and the Spanish autonomous communities.

Results

The ADW model herein attached and presented was done exhaustively, containing all provisions which are regarded as lawful and possible. Therefore, it is possible that patients delete the item II, as well as any or some of the procedures listed in each of the clinical conditions in item III. In addition, item V.1, which tells the name and professional registration number of the physician who assisted the grantor, can only appear when there was an express acceptance of the doctor. This model is grounded in six categories and is the result of a systematic review of the literature on advance directives, the comparison between the U.S. models and all models of the Spanish provinces, as well as the interviews.

Values and wills

As ADW are instruments of patient's self-determination it is imperative that, aiming at guiding decisions of the medical staff and the appointed representant, it is clear which values underlie the patient's life and what are the patient's wills.

Starting from the pure autonomy model of Beauchamp and Childress [17], one *that only applies to patients who have already being autonomous and expressed an autonomous decision or relevant preference* [17], one realizes that the living will follows the model of pure autonomy, while the enduring mandate follows the model of substitute judgment. I.e., the ADW, containing patient's guidelines and the appointment of an attorney, include both models.

The U.S. state of Maryland and [18] the Spanish province of Galicia [19] include in ADW a topic in which the patient details in writing, thoroughly, all their values and wills that need to base medical decisions. It is seen in that topic the possibility to avoid the difficulties faced by the healthcare team before the conflict between the patient's will and family wishes.

The E4 interviewee, when asked about how he deals with the conflicts between the wills of the patient and family, thus stands: "... *I also understand that that individual has to convince his family about respecting his will, because in many circumstanc-*

es ...". We must agree that this convincing is an arduous task because it tends to inflame the animosity between the parties and, moreover, cannot be regarded as an obligation of the patient given that the expression of intention of acceptance and refusal of treatment is a personal right, which is independent of family wishes.

Thus, it is believed that to give the grantor the possibility to make it clear in the ADW what their values and desires that should guide decision-making is important to prevent/help resolving these conflicts.

Decisions about the end of life

Decisions about the end of life are at the heart of the ADW. The literature on the subject, the ADW models studied and interviews pointed to three general medical conditions in which it is possible to talk about making decisions about the end of life, terminal illness, PVS and advanced dementia.

Terminal illness is one in which the patient's condition *is irreversible and incurable and death is expected in the next six months* [20]. The PVS is when the patient is in *a clinical condition of complete absence of awareness of himself and surroundings, with sleep-wake cycles and complete or partial preservation of hypothalamic and brainstem functions for more than three months after cerebral anoxia and twelve months following head trauma* [21,22] . Finally, advanced dementia is the clinical status in which the patient has altered motor function, loses self-awareness and reaction to pain and prognosis of neurological recovery is irreversible [20].

It shall be noted here that only the ADW model of the U.S. state of Mayne [23], among all that were searched, includes dementia as a clinical condition in decision making at end of life. Moreover, the study of the growing elderly population in Brazil [24] and the recognition that the pathologies that affect this population are multifaceted, causing loss of capacity of the individual, as proves literature as well as the interviews, admit the necessity of including this clinical condition in ADW. The E5 interviewee has confirmed this, indicating that the elder patient loses his capacity of contact:

"Because he is with dementia, and he is ... is ... losing a lot of other things, motor skills, he needs help, he becomes increasingly dependent, this is what I think that needs to be decided very early because his cognition is being lost ... ".

However, it appears that it is not enough that the grantor claims, generally, that he wishes the suspension of futile treatments. This practice, common in current Spanish models and in the first North American models, generates much of the criticism regarding ADW, founded on the general nature of those documents. It is necessary, therefore, that the patient describes the more specifically as possible what are the procedures and medications which suspension he refuses and/or admits.

Except refusing to artificial nutrition and hydration (ANH), all enrolled procedures are supported in the literature [25] and have already been used without qualification in the U.S. and Spanish models. The interviews corroborated the literature and the above mentioned models. In this respect, E4 was emphatic in stating that the refusal to invasive measures:

"The patient who is already affected by an advanced disease, a very advanced cancer with metastasis in vital organs, either brain, either lung, or either liver, and who determines willingly that in case of a higher complication he does not want to go into an ICU, or through some kind of invasive measurement, respirator, something like that, (...) I fully agree with this kind of attitude.".

E2, in turn, makes the following statement: *"And what is more common, what we do until then is... denying antibiotics, denying mechanical ventilation, is to enable a patient with respiratory failure to continue in respiratory failure, we do sedation in patients with cancer, we do sedation for these patients when they are aware, we do sedation for them, right?! And… We remove mainly those interventions."* E1 thinks that it *"would be ethically acceptable, in my view, you know, not to do tracheostomy in case, let's say, of an illness, leaving the oncology palliative care and entering the palliative care in non-cancer patients, which is too difficult for us right?!".*

Regarding the suspension or non-realization of ANH, there is a controversy between literature, models and interviews, especially in the case of PVS since the suspension of ANH in this type of patient will cause his death [26]. Critics claim that nutrition and hydration are basic care and that its suspension invariably gives rise to death, featuring euthanasia. In such cases, patients die of hunger and thirst, which goes against the interpersonal solidarity [27].

Favorable ones, which constitute the majority position, say the ANH can only be considered as basic care when it improves quality of life, which is not the case in most situations as the ANH generates

damage and discomfort to the patient. For this reason, they believe, it should be considered a medical treatment that replaces a function, as well as mechanical ventilation and dialysis [27,28]. Models of the U.S. states of Arkansas and Ohio [29 30] bring the possibility of refusing ANH. There is no such prediction in the Spanish autonomous communities' models.

The respondents were reluctant to discontinue ANH. E2 states that *"the removal of hydration, especially hydration, I think the enteral diet... I think it is possible, hydration I have enough trouble still... to consider it."* Then, when asked him why did he say that he has a major difficulty with the suspension of hydration, to which he answers: "*Because I consider that can lead to suffering".*

E1 says he has *"great peace to handle suspensions in cancer, palliative care in cancer, but not palliative care in non-cancer patients I... I... I recognize that it is very difficult... because we... the... the... the time of evolution of these diseases, the... issue of prognosis is very difficult... so I never know if my patient that... is suffering from a chronic, incurable disease, is... if he develops any clinical complication I never know if this will be the mechanism of his death.* (...) *Thence comes the whole issue of clinical contextualization, right?* Still stating that even *in cancer, literature shows that cancer produces few substances that generates the syndrome of cachexia and anorexia, so it is ok for us to suspend"*.

Manifesting on the suspension of ANH in PVS, E1 says: *"I do not suspend nutrition and hydration to these patients, unless I have a longitudinal follow-up and see that this patient he is... I, I, I can see this drop of functionality and... And actually draw a picture of death really coming... Then I have tranquility... But if I meet that patient only once I don't have tranquility in doing any clinical decision from this point of view...".* Regarding this issue, E3 mentions:

"It is very difficult a patient to accept not to receive hydration, not to receive any type of nutritional support, even though he has a more serious disease. It is... when the lifetime is still a reasonable amount of time I think it shall be offered and should be somehow adjusted somehow when that patient has no restraint, when the patient has a very short lifetime, few hours, few days, it loses a little sense and most of the time when the process is well managed the family understands, the patient understands, we are able to give that support with little hydration, or almost none, without any invasive measure using catheter, for some kind of diet".

E4 draws attention to the need to involve the entire team in making this decision *"because that is a great taboo, I need... I'm not alone taking care of patients, even if there is a family relationship, legal representative and a very good doctor there are always others involved in the intensive care patient who may see things differently, it always needs to have a negotiation that is particularly difficult at this level. Hydration and... and... and... and food is very basic to life, so we also will depend even if we were healthy, it would depend to continue living, it's complicated"*.

E5, when asked whether to suspend the ANH, replied that *"if the law permits yes. That is the following. This is a discussion that we had so much in ICU... Sometimes things are contrary to what we think but we have to obey the law, otherwise we put everything at risk, the... the... even the people and society at risk if we do not obey the law"*. It is perceived by the transcription of the speeches, that the reticence in the suspension of ANH is grounded in cultural and not technical reasons. That is, the concern of respondents to suspend ANH resides, in most cases, in the lack of longitudinal contact between doctor and patient and the cultural issue that the suspension of ANH brings suffering to the patient.

Even before this controversy, the survey has included the possibility that the patient refuses to ANH, given the consensus in the literature about the character of the ANH treatment, even in PVS. Research has proved that the main fear before the acceptance of this suspension – the possibility that the patient feels hunger and thirst – is not true. The discussion on the subject stems from individual and cultural values rather than technical criteria. For this reason, the health professional still requires directions from CFM and the Legislature, as well as education in order to avoid medical fear of being prosecuted for carrying out the will of the patient. Anything goes if a patient refuses to be artificially nourished and hydrated and health professionals agree not to respect their wills.

Attorney for health care at end of life

The coexistence of enduring mandate and the living will in a single document, or in other words, the making of a ADW policy increases the certainty that the patient's wishes will be fulfilled, because the attorney may decide by the patient when the living will is silent, and more, he can help medical staff when the family is against the wishes expressed in the living will. This is because, despite the binding aspect of the living will, it was clear from the inter-

views that the doctor feels difficulty in respecting the patient's wishes, even if they are written, when the whole family is contrary to that will. The E5 interviewed thus stands:

"Imagine the situation in which the patient has manifested, elaborated, notarized and recorded and no family supports his decision... The doctor he is a terrible situation if he's unconscious, if he's aware that's ok, not there, he is aware I'm going to do what he wants. But if he's unconscious, to have the whole family contradicting what he wrote, is a delicate situation, it is difficult to face because... is... he has no autonomy... They are taking responsibility for him, someone is taking responsibility for him... I think... but before a contrary family contradicting the… I find it hard... I think the ideal is to have a representant, at least that is one more person... no, he is the representant, he agrees it's done... ".

A U.S. study says that 39.4% of citizens who do some type of medical decision-making document opt to do the living will and enduring mandate in the same document, while only 21.3% make only the enduring mandate and 6.8% only the living will [31]. The difference between people who do the living will and the enduring mandate may be partly explained by the fact that the enduring mandate has a wider scope, given that it may be used for temporary discapacity, if this is not included in living wills. Moreover, this breadth of scope of the enduring mandate explains why critics of the living will, in general, are favorable to the enduring mandate.

So the ADW model proposed in this research contains the provisions of the grantor's will, which constitutes the living will, and also the appointment of attorney for health care, which is the enduring mandate. Therefore, following the American models of ADW, it is suggested the appointment of a chief prosecutor and two substitutes, in order to ensure that if the chief prosecutor is not found or is unable to make decisions, others can do.

It should be noted, however, that as the enduring mandate also covers situations of temporary discapacity, it is argued here that the grantor still has an enduring mandate separated from his living will, which justifies the fact that they suggest in the ADW proposed model the nomenclature "attorney for health care at end of life".

Other dispositions

Decisions about the end of life and the appointment of an attorney are the essence of ADW, but do not exhaust it. Considering that this document contains the expression of intention concerning the end of life and will be used when the patient cannot communicate, and that when it is proposed a model one must keep in mind that one of the goals is to popularize it, and possibly make it of easy access to people, we have chosen a topic of general dispositions, following the model of the U.S. states of Alaska [32], Colorado [33] and the Spanish province of Valencia [34]. In this model, the grantor recognizes to be aware that all palliative care will be carried out in order to guarantee his/her quality of life, even if they eventually can prolong it.

The model also requires the declaration of the grantor to be aware that no act of euthanasia can be performed and that the document binds the entire medical staff, family and friends. It is also predicted that women can make clear the knowledge that if they are pregnant ADW will be suspended until the end of pregnancy. And finally, the grantor can mention his/her desire to be taken home in order to die there.

It is important to note that this category did not include the item on organ donation that is present in U.S. and Spanish models above mentioned. This follows from the fact that organ donation in Brazil is regulated by Law 9.434/97 [35], subsequently amended by Law 10.211/01 [36], which provides for the need of the spouse or relative of greater age's authorization, being obeyed the line of succession, so that donation actually occurs. That is, according to this law the will of relatives overrides the will of the patient, thus going against the foundation of ADW: respect for the patient's wills. With it, it is here reaffirmed the position already assumed in previous works [37], that the disposition on organ donation in a Brazilian ADW would generate an institutes shock and, moreover, it would denaturize the ADW, given that they are, in essence, legal business indeed *inter vivos* [37], whose main object is to ensure the autonomy of the subject and the treatments that will be submitted in case of terminally life.

Guidelines for medical staff

One of the major points of disagreement about the ADW is the doctor's role in the making of the document. The CFM Resolution 1.995/12 provides in its Article 1, §4 [13] that it is the physician responsibility to register the ADW in the medical record when they are directly communicated by the patient. However, it is known that such a document, despite representing the consent from the patient, interferes greatly in medical management and most

of the time the grantor is technically vulnerable to do so, requiring information from the doctor.

This situation became clear in the interviews. E5 says *"I think it's impossible the person to do without consulting the doctor"* . E4 understands that *"the doctor, even at this time, he advises the patient about it* [range of pathologies]*"* . E2 emphasizes the role of the oncologist: *"especially the oncologist he should be more effective in these discussions with the patient, there is no way of being oblivious to this kind of discussion"*.

E2 summarizes the issue by establishing a correlation between autonomy and information: *"The autonomy it is absolutely dependent on the quality of information that the patient receives"*. Such statement is consistent to E4's: "*I understand that people can only make decisions if they are well informed, on anything, is not in the living will. I have to be very well supported from a technical standpoint so I can make a decision"*.

Contrary to expectations, the interviewer E1 proved to be reticent to discuss the role of the physician in making this document, questioning their preparation to help patients making their ADW:

"Hey, I have a certain reserve about discussing the role of the physician in making the living will because: I have is... some... elements in relation to my own professional colleagues, right? Because we know that the doctor he gets there the question of biopower, right? So the speech of the doctor has a heavy burden to the patient, so we have to be careful so that we don't... don't… okay… It is... is... directing and causing the patient to decide for some issues that he cannot elaborate at that time".

This concern was also expressed by E2: "*I have no doubts that the doctor is able to greatly influence a decision to this effect"*. The question raised by E5 concerns the preparation of physicians to assist the grantor: "*And I think the doctors they have to train a bit for it, because it is still a... despite having made the guideline it is not the medical culture, even in our midst, in our culture, many doctors are not trained to think about it, is... but I think we need to improve our speech, both doctors and patients, of seeking at the time of writing huh?!"*.

E4 shows concern regarding the intimacy between doctor and patient that is doing the ADW, stressing the importance of the professional, a figure that has been overlooked in health practice: "*I understand that one thing that has unfortunately been infrequently that is the patient's physician, right?!, the doctor who follows the patient for a long time, right?! It is the best person to inform that individual about the decisions that can happen"*.

The interviews allowed the perception that CFM Resolution 1.995/12 does not regulate satisfactorily the doctor's role in the making of the ADW. It was evident the need for the patient to be informed by the physician, to ensure his aid at the moment of making the document, given the fact that the doctor is the holder of the information, the one able to legitimize the patient's autonomy. For this reason, the doctor cannot be passive in the process, cannot only receive the ADW ready and write it down in the patient's medical record. We need to help the patient in the making of the document, giving the necessary information according to the patient's wills. It is also recommended that the physician authorizes the patient to mention his name in the ADW, so that the medical team that executes the document, if necessary, can contact him, but it is important to highlight that this mention can only be made with the express permission of the physician.

Based on these assumptions and models of the U.S. states of Alabama [38] , Texas [39] and Wisconsin [40] , it is understood the necessity of having a topic of guidelines for medical staff in the ADW, and it may contain, with the authorization of the professional, the name and professional registration number of the grantor's trusted physician, who has helped him in making the document as well as a summary of the purposes of the ADW and the information that the grantor was in full enjoyment of his/her civil capacity when preparing the document.

Finally, in compliance with the right of medical conscientious objection, which is engraved in the Code of Medical Ethics, in its Article 28 [41], within these guidelines it is important that the patient recognizes this right, stating that, once faced with conscientious objection, grounded, the patient shall be forwarded to another professional, aiming that the ADW is fulfilled.

It shall be noted that the four points of the item V – Guidelines for medical staff that will serve me (attached) are informative, especially items V.2 and V.3, which may sound redundant items. However, the goal is to direct the reading of the medical staff to those items, reaffirming the important points related to the capacity and knowledge of the situation in which their wills will be respected and, further, that the patient shall demonstrate in the ADW his worries for the team, recognizing even that professionals also have rights.

Revocation

The Law in Portugal provides a period of validity of five years for the ADW [9], following the placement of some scholars who argue that those documents are dynamic and cannot be forgotten after being elaborated, and the fact that medicine is constantly advancing would make it possible, thus, that a particular disease considered incurable at the time of drafting the document has become curable at the date of its application.

However, as stated in a previous study [37] , it is understood that the ADW are, in essence, revocable, which is why there is no agreement on the establishment of an expiry date for these documents, in full unnecessity, since at any time the grantor may revoke the previous expression of intention. Furthermore, the argument of the advancement of medicine is flawed as one of the limits of the ADW is the inapplicability of provisions contrary to Brazilian law and provisions contraindicated for the patient's condition, as well as refusal to treatments that have already been modified by medical science, so that the mere finding that medicine has advanced and that certain treatment is no longer used or recommended, are automatically and implicitly repealed.

For this reason, the ADW model proposed here contains a topic of revocation, in which the grantor certifies that he/she was informed of the possibility at any time to revoking the document by making a new policy or just a statement of revocation will, and may, through any of these, revoke the living will and/or enduring mandate, following the model of the U.S. state of Utah [42].

Discussion

The proposed model's conductive line is the detachment of generalists and formalized models such as forms, in which the patient only indicates the types of procedures and medications that he/she does not wish to undergo, without the possibility to discuss their wills and adapt the ADW to their specificity. These forms were based on the terms of informed consent (TIC) widely used in healthcare in the U.S. and imported to Brazil. What occurs is that its use can be compared to a contract of adhesion, especially due to the predisposition of clauses to be adhered by the patient [43], which goes against the essence of ADW.

An eventual perquisition on the possible use of the ADW model in doctors' offices and hospitals could, *a priori* , approach it to the TIC's forms. However, it is understood that both, the spaces of expression of subjectivity and as the list of procedures is characterized by providing examples, remove the possibility of framing this model into contracts of adhesion. However, it is recognized that the absence of legislation on advance directives in Brazil affects the implementation of this model, as the layman might question its legality. Regarding the physician, the Resolution CFM 1.995/12 determines the duty to follow the patient's wills, as expressed by the ADW. However, the suspension of ANH, although possible by an analysis of the literature, needs to be regulated in order to protect the professionals.

Regardless of the legality defense of the ADW even before the absence of a specific law in Brazil, the study of foreign experiences demonstrates its importance for regulating the specificities regarding the capacity of the grantor, the document's formalization process, its expiry date and also the creation of a national registry, the same as the Spanish [7] and Portuguese [9] *Rendav*. These issues were all discussed in a previous work [37], which concludes the need that the ADW is made only by a subject with discernment and, if a minor, that it requires judicial authorization to help the subject in the making of his/her ADW.

Concerning the formalization process, it is imperative that the ADW is drawn up by public deed before a notary, and registered in a Notary Office, with the formality of a declaration of intent, to ensure legal certainty. The creation of the National Registry of Advance Directives of Will is also recommended to enable greater effectiveness in fulfilling the will of the patient, so as not to risk the statement to be innocuous. Thus, considering the fulfillment of such formal arrangements, the Notary Office shall forward the ADW to the National Register within an extremely short time, in order to ensure its effectiveness. From a medical standpoint, it is important that the ADW is attached to the medical records, following the recommendations in Resolution CFM 1.995/12 [13].

With regard to its validity, it is understood that it shall not exist, due to the above mentioned arguments – which are restricted basically to the implied irrevocability of such documents. Finally, it is imperative to make an awareness campaign of Brazilian citizens about the importance of respecting the will of the family, in order to prevent conflicts between the will manifested in the ADW and the will of the family. As this campaign is a gradual effort, it is understood that in order to immediately try to mitigate the conflict of wills it shall be necessary for physi-

cians to talk with families when they inform them of the existence of the ADW and that hospitals maintain skilled psychologists and social workers available.

In sum, the proposed model will advance nothing if there is no collective effort to ensure that the will manifested in the ADW is fulfilled. The truth is that it is not enough to guarantee the right of individuals to express their will, it is still necessary to guarantee that his/her wills will surely be fulfilled. And this is the challenge that is now imposed.

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Participation of the authors

Luciana Dadalto has developed the thesis. Unai Tupinambás and Dirceu Bartolomeu Greco were, respectively, its co-advisor and advisor.

Received: Aug 28, 2013
Revised: Nov 4, 2013
Approved: Nov 14, 2013

Research article

Anexo

DIRETIVAS ANTECIPADAS DE VONTADE

Eu,_____(nome completo), _____(nacionalidade),_____ (estado civil), _____ (data de nascimento), _____(profissão),_____(CPF),_____ (endereço completo),_____, venho, de livre e espontânea vontade, no pleno gozo das minhas capacidades civis, respaldado pelos princípios constitucionais da dignidade da pessoa humana (art. 1º, III) e da autonomia (princípio implícito no art. 5º), bem como a proibição de tratamento desumano (art. 5º III), e pelo art. 15 do Código Civil brasileiro, expressar as instruções que devem ser levadas em consideração sobre meus cuidados médicos quando, por diferentes circunstâncias derivadas de um quadro irreversível de minha saúde física e/ou psíquica, eu não possa manifestar minha vontade:

I – VALORES E DESEJOS

Eu quero que todos saibam sobre meus valores e meus desejos, especialmente sobre o que é mais importante para mim durante a última parte da minha vida:

_____
_____
_____
_____
_____
_____
_____

II – DECISÕES SOBRE O FIM DA VIDA

II.1 Caso dois médicos entendam que padeço de uma doença terminal, incurável e irreversível, e que, portanto, não tenho nenhuma perspectiva de cura ou de melhora, manifesto aqui os procedimentos e medicamentos aos quais não desejo que sejam administrados ou realizados:

a) Ressuscitação cardiopulmonar, entendida como a abstenção da equipe de saúde em me reanimar caso meu coração pare de bater e eu pare de respirar;
b) Respiração artificial;
c) Grandes procedimentos cirúrgicos;
d) Diálise;
e) Quimioterapia;
f) Radioterapia;
g) Pequenas cirurgias que não servirão para me dar conforto ou aliviar minha dor;
h) Exames invasivos;
i) Antibióticos;
j) Nutrição e hidratação artificiais, pois reconheço que a Medicina já comprovou que em graus avançados de doenças terminais o paciente não sente fome nem sede e, mais, muitas vezes estes procedimentos podem trazer mais desconforto;
k) Outros: _____
_____
_____
_____
_____
_____
_____

II.2 Caso dois médicos entendam que padeço de uma demência em estado avançado e irreversível ou de uma enfermidade degenerativa do sistema nervoso ou muscular, em fase avançada e irreversível, nas quais eu não esteja mais vivendo com qualidade, entendido aqui qualidade de vida como _____
_____
_____
_____
_____
_____
_____
_____
_____
_____, manifesto aqui os procedimentos e medicamentos aos quais não desejo que sejam administrados ou realizados:

a) Ressuscitação cardiopulmonar, entendida como a abstenção da equipe de saúde em me reanimar caso meu coração pare de bater e eu pare de respirar;
b) Respiração artificial;
c) Grandes procedimentos cirúrgicos;
d) Diálise;
e) Quimioterapia;
f) Radioterapia;
g) Pequenas cirurgias que não servirão para me dar conforto ou aliviar minha dor;
h) Exames invasivos;
i) Antibióticos;
j) Nutrição e hidratação artificiais, pois reconheço que a Medicina já comprovou que em graus avançados de demências irreversíveis o paciente não sente fome nem sede e, mais, muitas vezes estes procedimentos podem trazer mais desconforto;
k) Outros: _____
_____
_____
_____
_____
_____
_____

II.3 Caso dois médicos diagnostiquem que estou em estado vegetativo persistente, condição que a Medicina tem uma grande certeza de irreversibilidade, manifesto

aqui os procedimentos e medicamentos aos quais não desejo que sejam administrados ou realizados:

a) Ressuscitação cardiopulmonar, entendida como a abstenção da equipe de saúde em me reanimar caso meu coração pare de bater e eu pare de respirar;
b) Respiração artificial;
c) Grandes procedimentos cirúrgicos;
d) Diálise;
e) Quimioterapia;
f) Radioterapia;
g) Pequenas cirurgias que não servirão para me dar conforto ou aliviar minha dor;
h) Exames invasivos;
i) Antibióticos;
j) Nutrição e hidratação artificiais, mesmo sabendo que no estado vegetativo persistente a não admissão de nutrição e hidratação provocará a minha morte;
k) Outros: _____
_____
_____
_____
_____
_____
_____

III – PROCURADOR PARA CUIDADOS DE SAÚDE NO FIM DA VIDA

III.1 Caso, no momento em que for constatada alguma das três situações clínicas acima expressadas, seja necessário decidir acerca de situações não expressadas por mim em minhas decisões sobre o fim da vida, nomeio:

Nome:_____
_____
CPF:_____
Endereço completo: _____
_____
Telefones de contato: _____

Opcional: Se esta pessoa, no momento em que for procurada, não for localizada ou estiver incapacitada de tomar decisões, eu designo um procurador substituto, que terá os mesmos poderes do procurador principal:

Nome:_____
_____
CPF:_____
Endereço completo: _____
_____
Telefones de contato: _____

Opcional: Se esta pessoa, no momento em que for procurada, também não for localizada ou estiver incapacitada de tomar decisões, eu designo outro procurador substituto, que terá os mesmos poderes do procurador principal e do primeiro substituto:

Nome:_____
_____
CPF:_____
Endereço completo: _____
_____
Telefones de contato: _____

II.2 Meus procuradores não podem revogar minha vontade aqui manifestada. Devem apenas sanar dúvidas que porventura existirem e tomar qualquer decisão relativa à suspensão de esforço terapêutico, não explicitadas neste documento, exceto as seguintes:

_____
_____
_____
_____
_____
_____
_____

IV – OUTRAS DISPOSIÇÕES

IV.1 Manifesto expressamente meu desejo de que sejam realizados todos e quaisquer procedimentos cuja finalidade seja, exclusivamente, prover meu conforto e amenizar minha dor e/ou angústia, garantindo um final digno de vida, mesmo quando tais procedimentos possam prolongar minha vida.

IV.2 Não desejo a realização de nenhum procedimento para tirar minha vida, desejo apenas que ela não seja desarrazoadamente prolongada.

IV.3 Se eu estiver grávida, essa diretiva antecipada ficará suspensa até o final da gravidez.

IV.4 Tenho plena consciência que este documento vincula meus familiares, meus amigos e a equipe de saúde, que devem seguir todas as disposições aqui inscritas.

IV.5 Desejo que, diante da irreversibilidade do quadro médico, eu seja levado para minha casa a fim de que desfrute dos últimos momentos de vida junto com a minha família e no meu lar.

V – DIRETRIZES PARA A EQUIPE DE SAÚDE QUE ME ATENDERÁ

V.1 Durante a feitura deste documento fui orientado pelo meu médico de confiança, Dr. _____ _____, portador do CRM nº _____, que me instruiu acerca dos termos técnicos aqui escritos, bem como das consequências de todos os procedimentos aos quais estou me recusando.

V. 2 Esse documento autoriza a suspensão ou não realização de procedimentos apenas quando dois médicos atestarem a irreversibilidade da condição de terminalidade, de demência avançada ou de estado vegetativo.

V.3 Este documento foi feito por uma pessoa em pleno gozo de sua capacidade civil que, de acordo com as leis brasileiras e a Resolução nº 1.995/2012 do Conselho Federal de Medicina, tem a faculdade de recusar procedimentos médicos que tenham a finalidade apenas de prolongar a vida biológica, sem garantir-lhe qualidade de vida.

V.4 Se algum membro da equipe se utilizar de seu direito à objeção de consciência e, portanto, não puder cumprir as disposições aqui previstas por razão moral ou religiosa, vocês devem me encaminhar para outro profissional a fim de que minha vontade seja cumprida.

VI – REVOGAÇÃO

Tenho ciência de que posso revogar essa diretiva antecipada de vontade a qualquer tempo, fazendo uma nova diretiva ou apenas uma declaração de vontade revocatória. Em ambos os casos, posso revogar minhas decisões sobre o fim de vida e/ou a nomeação do(s) procurador(es) para cuidados de saúde no fim de vida.

Cidade, data completa

_____

_____

Assinatura do outorgante

_____

Assinatura do procurador principal

_____

Assinatura do procurador substituto 1

_____

Assinatura do procurador substituto