

Advance Directives in Uruguay: Incorporation into Medical Practice Today
Directivas anticipadas en Uruguay: Incorporación a la práctica médica en el presente
Diretrizes antecipadas no Uruguai: Incorporação à prática médica hoje

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Abstract: Introduction: Law number 18473 on advance directives was enacted in Uruguay in 2009, being regulated four years later. This shows a propensity towards autonomy and planning for the future of patients. Objective: To determine health professionals' knowledge of the law, its use in the clinic and access to the advance directives form. Method: Descriptive research, by means of an anonymous survey of Uruguayan general practitioners and specialists in activity, sent through social networks. Results: 363 responses were obtained, with 97 % of the professionals who were attending patients, 79.5 % had not issued the document and more than 50 % were unaware of the law. Conclusion: Knowledge of advance directives in the Uruguayan medical profession is scarce and its application to patients is even scarcer.

Keywords: living wills; personal autonomy; advance directives; end of life.

Resumen: Introducción: La ley número 18473 de voluntades anticipadas fue promulgada en Uruguay en el año 2009, reglamentándose cuatro años después. Esto evidencia una propensión hacia la autonomía y la planificación del futuro de los enfermos. Objetivo: Determinar el conocimiento por parte de los profesionales de la salud en cuanto a la ley, su empleo en la clínica y acceso al formulario de voluntades anticipadas. Método: Investigación descriptiva, mediante una encuesta anónima a médicos uruguayos generales y especialistas en actividad, enviada por redes sociales. Resultados: Se obtuvieron 363 respuestas, con un 97 % de profesionales que atendían enfermos, un 79,5 % no habían extendido el documento y más del 50 % no tenía conocimiento de la ley. Conclusión: El conocimiento sobre las voluntades anticipadas en el cuerpo médico uruguayo es escaso y es aún más su aplicación a los pacientes.

Palabras claves: voluntad en vida; autonomía personal; directivas anticipadas; final de vida.

Resumo: Introdução: A lei número 18473 sobre diretrizes antecipadas foi promulgada no Uruguai em 2009, sendo regulamentada quatro anos mais tarde. Isto é uma evidência da propensão para a autonomia e o planejamento do futuro dos pacientes. Objetivo: Determinar o conhecimento da lei por parte dos profissionais de saúde, seu uso na clínica e o acesso ao formulário de diretrizes antecipadas. Método: Pesquisa descritiva, utilizando uma pesquisa anônima de clínicos gerais uruguaios e especialistas em atividade, enviada através de redes sociais. Resultados: Foram obtidas 363 respostas: sendo 97 % dos respondentes eram profissionais que estavam atendendo pacientes, 79,5 % não tinham emitido o documento e mais de 50 % desconheciam a lei. Conclusão: O conhecimento das diretrizes antecipadas na profissão médica uruguia é escasso, e sua aplicação aos pacientes é ainda mais escassa.

Palavras-chave: testamento quanto á vida; autonomia pessoal; diretrizes antecipadas; fim de vida.

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Introduction

Advance directives are a tool to ensure patients' right to make decisions regarding their health care, especially at the end of life. ⁽¹⁾ Along these lines, people's rights have had a push towards human rights, moving from a welfare state towards a new model with people-centered guarantees and transparency. ⁽¹⁾ In the biomedical field, a sick person has ceased to be an object of study, to assume an active role in their relationship with the health professional in decisions about procedures, interventions, and treatments. According to this, the person is placed at the center of the process, favoring their dignity and autonomy of choice. ⁽¹⁾

In this logic, Uruguay took an important step with the law No. 18,473, which was regulated in December 2013 and entered the legal order of Uruguayan under number 001-2735 / 2013. In article 1, the law states "Every person of legal age and mentally fit, voluntarily, consciously and freely, has the right to oppose the application of medical treatments and procedures unless this affects or may affect the health of third parties". ⁽²⁾ This does not mean that through advance directives it seeks to legalize euthanasia but, on the contrary, it is sought that the person enjoys a dignified life, without being subject to treatments that go against their conception of what a dignified life implies. This is made explicit in the following expression: "the right to die with dignity is not a right either to assisted suicide or to a solitary flight from the theater of life, but to live death with dignity, that is, being cared for, assisted and respected until the end". ⁽³⁾ Accordingly, the human considers itself a person and therefore free to determine its life, its own morals, its own behavior, and answer for its actions. ⁽⁴⁾ Therefore, people can use advance directives to make

decisions about their life, their health in the future and what they want for, counting on professional advice, which clarifies the doubts and the consequences of their actions. ⁽⁵⁾ Said advance directives are defined as:

Written unilateral statements, addressed to health personnel and other significant persons, where a person of legal age expresses the treatments that he / she wishes or does not wish to be applied in various future medical circumstances, so that they may direct the medical decision-making when they no longer have the ability to express themselves. ⁽⁶⁾

It is also defined as a:

Declaration of will made by a competent and capable person of legal age, by means of which they express their will in advance to leave expressed instructions related to the making of decisions related to their health, in case of suffering an irreversible terminal illness or other event, to be taken into account when circumstances arise that do not allow them to personally express their will. ⁽⁷⁾

Within the health care teams, it is the palliative care teams that reinforce the importance of the declaration of advance directives. This is done as a way of respecting the autonomy of patients, to promote with dignity a process of imminent death, allowing patients to express their wishes with a guarantee that it will be fulfilled. ⁽⁸⁾

Regarding the registration of advance directives, the document to register people's will began in the United States in 1967, proposed by the Euthanasia Society of America. The lawyer Louis Kutner in 1969 proposed its content and the document model in his work "Due process of euthanasia: the living will, a proposal". ⁽⁹⁾ Later in time, in the same country, in 1990 the Patient self-determination act (PSDA) was approved, the first federal law that recognized a patient's right to self-determination, which sought to inform the public about the directives and encourage their use, proposing the resolution of ethical conflicts. ⁽¹⁰⁾ Research has been conducted since the approval of the law, including the "Study to understand prognoses and preferences for outcomes and risk of treatments (SUPPORT)". The results showed the need to broaden the perception of the subject, prioritize documents and communication processes. ⁽¹¹⁾

In Latin America, laws regarding directives or advance directives were enacted in Puerto Rico, Argentina, Mexico, Colombia, and Brazil. In 2001, Puerto Rico was the first country to regulate a law that addresses the right to privacy and recognizes the autonomy of an individual. In Argentina, directives began to be instituted first in the provinces and, later, at the federal level, arriving in 2012 to promulgate law number 26742. In Mexico, the advance directives law was enacted in 2008. This document may be prepared by any capable individual, diagnosed terminally ill and by family members, when the individual is prevented from manifesting. In Colombia, the issue of advance directives was addressed in the code that regulates access to palliative care with Law 1733/2014. In Brazil they have not been specifically regulated in the legal field. ⁽¹²⁾

In the mid-90s, the first proposals for legal regulation of these documents began to be heard in the regional parliaments of Spain. On November 15, 2002, Law 41/2002, of November 14, basic regulation of the autonomy of the patient, their rights, and obligations in terms of information and clinical documentation, ⁽¹³⁾ is published in the Official State Gazette (BOE), number 274.

As for the research in this regard, Solsona et al, collected information from the first-degree relatives of 80 patients admitted to the ICU, to learn about some aspects of the clinical decision-making process with their families. According to their relatives, none of the patients had drawn up a "living will", and only 10 had verbally appointed. However, in no case was it done in writing with a decision-making representative. ⁽¹⁴⁾ For his part, Santos de Unamuno, in 2003 carried out a cross-sectional descriptive study with a survey of 132 users of a consultation in a Primary Care health center, after having received written information about the previous instructions. The results showed that 40% of the respondents would be willing to fill out an advance directive, and another 40% believed it possible, although not sure. 32% said they had spoken "clearly" with their family before about end-of-life care, and 31% said they had done so "superficially". ⁽¹⁵⁾

In another study with interviews of 331 people in two basic health areas in Toledo, Spain, a primary care group found that 88.5% did not previously know the advance directive document. After informing them, 70.6% would sign it if they suffered a terminal illness, while 55.1% would do so at the present time, without differences by sex or beliefs. ⁽¹⁶⁾

A study carried out by Jaya Virmani and collaborators, tried to verify the ability of these documents to stimulate communication between the doctor and the patient. They interviewed 115 seriously ill cancer patients and 22 of their doctors. 30% of patients said they had not had any discussion about treatment decisions with their doctor. Most physicians were ignorant of advance directives. ⁽¹⁷⁾

Brendan M. Reilly and colleagues sought to know if patients really want to discuss these issues with their doctor. They interviewed 258 patients admitted to an intensive care service. 81% of the patients interviewed, with decision-making capacity, had dialogued or wanted to discuss advance directives at the hospital. In this scenario, patients admitted to hospitals need to talk about advance directives, although this is not taken advantage of by health personnel. ⁽¹⁸⁾

This study aimed to identify the knowledge and use of the advance directive form of the Uruguayan medical body in clinical practice. Among the specific objectives, it is proposed to inquire about the knowledge of the current legal framework, how to access the form and where to obtain the information for its use.

Method

A descriptive study was carried out through an anonymous survey, using non-probabilistic chain sampling, using as a tool the resource of social media, WhatsApp, and Twitter. Doctors of all specialties, public and private workers, from all over the country were recruited in the last two weeks of August 2019. The invitation was sent by smartphone to groups of doctors where the researcher was part, through a message with a link to a website located on Google forms. There, the informed consent letter and the survey could be found. Each participant was asked to forward this link to their medical contacts, in order to increase the number of responses. Duplicate responses were prevented with the given characteristics of the website by reading the IP number from which the survey was carried out, but it was not prevented from doing so if it used several devices.

The inclusion criterion used were to be part of social network groups of doctors in the country. Due to the characteristics of the methodology used, it was not possible to calculate the sample size beforehand.

Five age ranges were defined, from 25 to 35 years old, from 36 to 45 years old, from 46 to 55 years old, from 56 to 65 years old and over 65 years old.

Information was requested to evaluate the knowledge about the advance directive document and its use, the area of professional performance, the care of patients in their workplace and if they had filled out the advance directive form for themselves.

The data were stored in office automation software and processed using the SPSS v 19 program. The principles of confidentiality and anonymity were preserved. Each of the doctors who were invited to participate knew the purpose of the study through a prior consent letter. The letter informed that it was a scientific study with an ad hoc survey, in which no personal or work data would be requested. Also, the survey could be suspended at any time. They would not receive remuneration for such a survey. Regarding personal data, the researcher's email and telephone number were available in order to evacuate doubts. By clicking on the acceptance button, they would be signing the consent.

Results

With the data obtained, tables were generated with office software, interested in knowing only the relative and absolute frequencies. 363 responses were obtained from the survey sent in the last two weeks of August 2019, constituting 2.37% of the total number of doctors, according to the study carried out by the Uruguayan Medical College in 2017.⁽¹⁹⁾ 77.2% of the responses were from female doctors and 22.8% from male doctors.

Table 1 shows the knowledge of the document in relation to the age ranges of the surveyed population.

Table 1. Age ranges and knowledge of the advance directive document (ADD)

Age groups (N = 363)	Relative Frequency	Knowledge of ADD
25 to 35 years	16.0 %	36 %
36 to 45 years	41.6 %	43.9 %
46 to 55 years	23.3 %	48 %
56 to 65 years	17.4 %	43 %
more than 66 years	1.7 %	-

Source: Own elaboration (2021)

Of the 355 responses to whether they knew the advance directive document, 43.9% of doctors knew it, and 56.1% did not know it. According to the age groups 36% of the doctors between 25 and 35 years old knew the advance directive document, 43.9% between 36 and 45 years old, 48% between 45 and 55 years old and 43% between 56 and 65 years old, while those over 66 years of age did not answer.

Regarding whether they knew the current regulations and the national law, of the total of 239 responses, 44.4% knew it and 55.5% did not know it. Of the 354 responses, to whether they cared for patients in their daily work, 97.5% did so.

According to the performance area, it can be seen in Table 2.

Table 2. Work performance area

Work performance area	Relative frequency (N= 363)
Polyclinic	32 %
Emergency	19 %
Hospitalization / Floor	12.2 %
Closed area	10.2 %
Emergencies	8.5 %
Palliative care	7.1 %
Radio / address	6.8 %
Individual, management, etc.	4.2 %

Source: Own elaboration (2021)

Of the total of 223 responses to whether they had extended the form to a patient, 20.6% had done so and 79.4% had not. Of these refusals, 10.6% say that it did not correspond to them, 10.6% because the patient did not request it, 22.7% did not take it into account, 2.4% did not have time, 11.4% because the provider did not have them, and 42.4% referred that there were other reasons.

Out of a total of 338 responses to whether the professionals had signed advance directives, 96.2% had not done so, referring to 7.7% that they are young, 1.5% are not interested, and 16.3 % did not cross their mind and 74.5% other reasons.

71.6% of the total did not know how to access the advance directive form.

Regarding the question to where or which source they would turn if they required information about the law or the documents, a summary can be seen in Table 3.

Table 3. Place to search for information on the law and the advance directive document

Information search about ADD	N=363
MSP	30.1 %
Internet	23 %
Another colleague	17 %
Bioethics Committee	9.9 %
Health provider	5.7 %
Medicine School	5.1 %
Medical union	3.1 %
Other places	5.1 %

Source: Own elaboration (2021)

Of the 156 doctors who knew the advance directive document, only 105 were aware of the regulations, and only 39 had extended it to their patients, these have been 13 in polyclinic, 10 in palliative care, 6 in hospitalization or floor, 3 at home or radio, 3 in closed areas, 2 in emergency, 1 in private consultation, 1 in management. Of the 25 palliative care physicians who responded to the survey, only 10 had extended the form to their patients.

Discussion

The collection method was accessible with basic computer tools, although the disadvantage, being that it is random, depends on the willingness or time available of the participant who receives it to do it and share it. Female professionals answered four times more than male professionals. Regarding the knowledge and current regulations, half of the participating doctors are aware of its existence and the law that supports it. In relation to this, a study showed that more than half of the respondents expressed their limited level of knowledge.⁽²⁰⁾ Another research found that 63.4% of health personnel affirm their lack of knowledge about advance directives and their legal framework.⁽²¹⁾ Along the same lines, another study found that 82,5% of primary care professionals reported little or no knowledge of advance directives.⁽²²⁾ An observation in New Zealand demonstrated a lack of common and legal knowledge about advance directives and little experience in healthcare personnel.⁽²³⁾ Among other sources consulted, it was shown that 92% of health personnel know what the directive of advance directives is, but almost the same percentage do not know the content of the laws. In this same study, patients have not requested it.⁽²⁴⁾

Almost all of the Uruguayan doctors surveyed affirm that they treat patients in their workplaces, but only 20.6% have extended the advance directive form. This value found is slightly higher than the one referred to in the Peicius study, which showed that only 16.7% of the surveyed doctors have issued the document.⁽²⁰⁾ Within the practical clinical implications, both health personnel and patients do not have access to the instrument of advance directives, not allowing adequate informed and autonomous decision planning.⁽²⁵⁾ The low percentage of palliative care physicians who issued the advance directive form is

striking. A higher percentage was expected, since these professionals must carry out advance planning of end-of-life decisions in their daily work.

Conclusions

The results of the survey show that the knowledge about advance directives in the Uruguayan medical body is scarce, as well as its application to patients. More information will be needed from health service users' and more training for doctors. The advance directive document is an essential tool to safeguard the autonomy of the patient and decision-making. The law previously expressed in its article 10, section b, indicates that "the public and private institutions that provide health services must provide educational programs for their personnel and users, on the rights of the patient as stipulated in this law, and the Ministry of Public Health must implement a wide diffusion".⁽²⁾ From this, some questions arise: Why don't palliative care physicians offer advance directives to patients? What could the implications for patients be regarding ignorance of the regulations on the part of medical professionals? Is it possible that patients' rights are being violated?

These questions leave open the opportunity to delve into these topics.

It is advisable to propose research lines that evaluate the application of advance directives after a training period.

Among the limitations of the study, the reduced number of responses obtained is worth highlighting. Another limitation is the carrying out of the study without a prior pilot test, as well as the failure to present it to an Ethics Committee, although the safeguards were taken through informed consent. This limits the conclusions but opens the gaze to improve this study when replicating it.

It is essential to create a close bond with patients, generating trust, providing the right information at the right time, helping in planning decisions.

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