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Knowledge regarding advance directives in a teaching hospital

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Abstract

This study evaluated the knowledge of health professionals and users regarding advance directives in a Brazilian teaching hospital. The study sample comprises 145 participants – 66.9% of them health professionals and 33.1% users. Most participants had no knowledge about advance directives, with a higher incidence among users (61.9% of professionals, 91.7% of users; $p<0.001$). After learning about advance directives, 97.9% of professionals and 95.8% of users ($p=0.60$) stated that individuals should draft directives and that physicians were responsible for initiating the conversation (56.7% and 58.3%, respectively, $p=0.71$). After the research, 73.2% of professionals and 58.3% of users ($p=0.19$) thought about drafting directives. In conclusion, knowledge on the subject is still less than ideal in health care in the teaching hospital evaluated, especially among users.

Keywords: Living wills. Advance directives. Knowledge. Perception.

Resumo

Conhecimento sobre diretivas antecipadas de vontade em hospital-escola

O objetivo deste estudo foi avaliar o conhecimento de profissionais de saúde e usuários sobre diretivas antecipadas de vontade em hospital-escola brasileiro. Aceitaram participar 145 pessoas, sendo 66,9% delas profissionais de saúde e 33,1%, usuários. A maioria dos participantes não conhecia diretivas antecipadas de vontade, com maior incidência entre usuários (61,9% dos profissionais, 91,7% dos usuários; $p<0,001$). Após serem instruídos acerca das diretivas antecipadas, 97,9% dos profissionais e 95,8% dos usuários ($p=0,60$) afirmaram que pessoas deveriam elaborar diretivas e que a responsabilidade de iniciar a conversa era do médico (56,7%, 58,3%, respectivamente, $p=0,71$). Após a pesquisa, 73,2% dos profissionais e 58,3% dos usuários ($p=0,19$) pensava em elaborar diretivas. Conclui-se que o conhecimento sobre o tema ainda está aquém do ideal no campo assistencial no hospital-escola avaliado, sendo menor entre usuários.

Palavras-chave: Testamentos quanto à vida. Diretivas antecipadas. Conhecimento. Percepção.

Resumen

Conocimientos sobre directivas anticipadas de voluntad en un hospital docente

El objetivo de este estudio fue evaluar el conocimiento de profesionales de salud y usuarios sobre directivas anticipadas de voluntad en un hospital docente brasileño. Un total de 145 personas aceptaron participar, el 66,9% de ellos profesionales de la salud y el 33,1% usuarios. La mayoría de los participantes no conocían directivas anticipadas de voluntad, con mayor incidencia entre usuarios (61,9% de los profesionales, 91,7% de los usuarios; $p<0,001$). Después de ser instruidos acerca de las directivas anticipadas, el 97,9% de los profesionales y el 95,8% de los usuarios ($p=0,60$) afirmaron que las personas deberían elaborar directivas y que la responsabilidad de iniciar la conversación era del médico (56,7%, 58,3%, respectivamente, $p=0,71$). Después de la encuesta, el 73,2% de los profesionales y el 58,3% de los usuarios ($p=0,19$) pensaba en elaborar directivas. Se concluye que el conocimiento sobre el tema aún está lejos del ideal en el campo de la atención en el hospital docente evaluado, siendo menor entre los usuarios.

Palabras clave: Voluntad en vida. Directivas anticipadas. Conocimiento. Percepción.

The authors declare no conflict of interest.

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Advance directives (AD) were defined in Brazil by the Federal Council of Medicine (CFM) in article 1 of CFM Resolution 1,995/2012 as being the *set of desires, previously and expressly declared by patients, about the care and treatments they want or do not want to receive when they are unable to express, freely and autonomously, their will*¹. This is an autonomous declaration of a person who, while conscious and informed, expressed their will about the treatments they intend to undergo or not when in a situation of terminal and incurable disease.

End-of-life declarations arose in the United States with lawyer and human rights activist Luis Kutner, who developed the concept of living will, a document that enabled people declare in advance concerning health treatments they would or would not accept to receive in case they were unable to communicate due to illness²⁻⁶. In the same country, in 1990, the first federal legislation known to exist was published, called the Patient Self Determination Act⁷.

End-of-life declarations of will are subject to the legislation of each country²⁻⁶. The North-American model⁷ established no fixed document format and required no registration in a database, but each North-American state can establish more or less restrictive specific laws⁸. The Australian model, described by the Consent to Medical Treatment and Palliative Care Act⁹, is a formal act that requires document registration and established a national registry of declarations. Portugal's model instituted a national registry database¹⁰.

In Brazil, AD are regulated by resolution from CFM¹, which instructs patients to speak to the assistant physician, and this professional is responsible for registering the directives in the medical record. However, the apparent ease generated insecurity in professionals and society alike^{2,3}. Most health professionals, including physicians, claim to be unaware of the directives, CFM's resolution and end-of-life ethical-legal issues^{6,11-13}, stating that the lack of a federal law or model could lead to judicialization^{4,6,11,14,15}.

As of the writing of this article, the subject had been addressed only in state laws that deal with the patient's right to information, therapeutic refusal, palliative care, and choice of place of death, such as Law 10,241/1999 of

the state of São Paulo¹⁶, Law 3,613/2001 of the state of Rio de Janeiro¹⁷, and Law 20,091/2019 of the state of Paraná¹⁸. Bills on palliative care, ADs and terminality of life were found in the Federal Senate: Bill 267/2018¹⁹ was withdrawn by the author, and Bills 149/2018²⁰, 493/2020²¹ and 883/2020²² remain pending.

Preparing AD involves awareness of the finitude of life and the processes of illness. Physicians must clearly inform patients about their current health status and what can be expected in the future. To decide on AD, patients must be functional, aware and clearly understand the probable outcome of accepting or refusing specific care procedures, as well as their own perception of quality of life. To define which items will be included and how they will be expressed in the directives, a cordial and truthful dialogue between the patient, family members directly involved in care, and the assistant physician is appropriate^{2,3}. As it is likely that other health professionals – such as nurses and nursing technicians – will be involved in care over time, it would be important that they understood what is involved in the declarations described in the AD of the patient under their care.

Thus, this study aimed to assess the knowledge and perceptions of health professionals (physicians, nurses and nursing technicians) and users (patients and companions) of the Unified Health System (SUS) on AD in a Brazilian teaching hospital and invite them to workshops on preparing the document.

Method

This is a cross-sectional study approved by the Research Ethics Committee of the Department of Health Sciences of the Federal University of Paraná and registered on Plataforma Brasil, following the recommendations for research with human beings in force in the country.

The authors developed a questionnaire to collect data on knowledge and perceptions about AD. This instrument was based on other questionnaires available in the literature, in articles that addressed the subject in the Brazilian territory²³⁻²⁵. Simple, multiple-choice questions were prepared, which could be

answered in up to ten minutes. The instrument developed was reviewed by three other physicians experienced in AD and tested in a pilot group of three physicians before being applied to the research participants. The final questionnaire contained three demographic questions and seven questions on the knowledge about AD, answered by alternatives.

All health professionals (physicians, nurses and nursing technicians) who worked in the care sectors of the medical clinic of a teaching hospital located in the city of Curitiba/PR were invited to participate in the research. We also invited SUS users (patients and companions) who were in the waiting room of the elective outpatient consultation sector at the same hospital, between January 20 and 31, 2020.

The participant inclusion criteria were: 1) being aged at least 18 years; 2) being willing and available to participate; and 3) understanding the research terms. Participants were volunteers, were not in urgency/emergency sectors, were instructed, and had the required time to read and sign the informed consent form.

Data were collected by three medical students trained for the research objectives. Potential participants were approached in the mentioned sectors and had the research explained to them – all doubts raised were clarified; the researchers evaluated inclusion criteria and applied the consent form, which, after being signed, had a copy printed and handed to the participants. Next, demographic data were requested and the questionnaire was verbally presented, opting for verbal collection to increase adherence and optimize the participants' time. The questions were read by the research assistants, who did not interfere with the answers.

To ensure data homogeneity, after applying question 1 and receiving its answer, all participants were instructed as to what would be considered

AD in this study, using the following standard text: "Advance directives are regulated documents in Brazil and in other countries that allow individuals to describe the treatments that they want or not to receive in case they are unable to communicate in the final stage of life." We made sure the participant understood the instructions before proceeding.

The obtained data were entered into an electronic spreadsheet, checked, compared by groups and submitted to a statistical analysis using Software R, version 3.6.1. Categorical variables were presented as absolute and relative frequencies, and quantitative variables as mean and standard deviation. For comparisons between categorical variables, we used Fisher's exact test or the chi-square test. The significance level adopted was 5% ($p \leq 0.05$).

Results

In total, 145 participants agreed to participate: 66.9% were health professionals and 33.1% were users. Of the professionals, 65 (67%) were women and 32 (33%) were men, namely: 30 (30.9%) nursing technicians, 7 (7.2%) nurses, 37 (38.1%) resident physicians, and 23 (23.7%) physicians hired in the service; mean age was 36.4 ± 10.5 years (ranging from 24 to 67 years). Of the users, 38 (79.2%) were patients and 10 (20.8%) were companions, namely: 35 (72.9%) women and 13 (27.1%) men; mean age was 48.6 ± 13.4 years (ranging from 19 to 71 years).

Most professionals (61.9%) and almost all users (91.7%) were unaware of any end-of-life declaration of will ($p < 0.001$). Among the participants who reported having knowledge about some document, 27 (27.8%) professionals and 2 (4.2%) users knew about AD. The data are presented in Table 1.

Table 1. Answers to questions about advance directives

Questions		Professionals (n=97) n (%)	Users (n=48) n (%)	p-value
1. Does the participant know about any document in which patients can describe treatments they want or do not want at the end of life?	Yes	37 (38.1)	4 (8.3)	<0.001*
	No	60 (61.9)	44 (91.7)	

continues...

Table 1. Continuation

Questions			Professionals (n=97) n (%)	Users (n=48) n (%)	p-value
If yes for the previous question: (professionals n=37; users n=4)	1.1. They mentioned “advance directives”	Yes	27 (73.0)	2 (50.0)	0.57*
		No	10 (27.0)	2 (50.0)	
	1.2. They know about CFM Resolution 1,995/2012	Yes	19 (51.3)	1 (25.0)	0.61*
		No	18 (48.7)	3 (75.0)	
	1.3. They have a formalized and written AD	Yes	0 (0.0)	1 (25.0)	0.09*
		No	37 (100)	3 (75.0)	
2. Does the participant believe that people in society in general should prepare advance directives?		Yes	95 (97.9)	46 (95.8)	0.60*
		No	2 (2.1)	2 (4.2)	
3. Who does the participant believe should initiate conversations about advance directives?		Physician	55 (56.7)	28 (58.3)	0.71#
		Patient	19 (19.6)	11 (22.9)	
		Other	23 (23.7)	9 (18.7)	
4. Would the participant respect the items described in the family members' advance directives?		Yes	86 (88.6)	38 (79.2)	0.22#
		No	2 (2.1)	3 (6.2)	
		I don't know	9 (9.3)	7 (14.6)	
5. Would the participant accept a family member's choice of dying at home if it were described in the advance directives?		Yes	86 (88.6)	34 (70.8)	0.02#
		No	4 (4.1)	7 (14.6)	
		I don't know	7 (7.3)	7 (14.6)	
6. Does the participant trust that their family members would respect advance directives and other end-of-life decisions?		Yes	62 (64.0)	25 (52.1)	0.11#
		No	14 (14.4)	14 (29.2)	
		I don't know	21 (21.6)	9 (18.8)	
7. Would the participant think about preparing their own advance directives after this interview?		Yes	71 (73.2)	28 (58.3)	0.19#
		No	14 (14.4)	11 (22.9)	
		I don't know	12 (12.4)	9 (18.8)	

* Fisher's exact test; # chi-square test; p-value significant if ≤ 0.05

Note: after answering question 1 and before questions 2 to 7, the participants were informed about what AD are with standard text – "Advance directives are regulated documents in Brazil and in other countries that allow individuals to describe the treatments that they want or not to receive in case they are unable to communicate in the final stage of life."

Discussion

In recent decades, life expectancy has increased. In the Brazilian context, life expectancy grew by 31.1 years since 1940 and, in 2019, a person born in Brazil expected to live, on average, 76.6 years, with women living seven years more than men. Longevity leads to changes in the illness profile, with a greater number of diagnoses

of chronic degenerative and oncological diseases and organ failure²⁶.

Treatments that make it possible to cure diseases or modify their courses have been largely incorporated into health care practice. Currently, patients – even those with serious, advanced and incurable diseases – can live increasingly longer. The illness process has become a long-term phase, surrounded by medical interventions

that can increase life span, but which not always add quality of life²⁷.

Respect for patient autonomy is one of the pillars of principlist bioethics²⁸, and AD are precisely intended to promote treatments in line with the person's values when they are unable to express their will at the end of life. Patients – who should be the center of health care – have the right to receive information about diagnoses, prognosis, and to participate in treatment strategies, in addition to having their personal values included in the care.

Patients have the right to accept or refuse what physicians propose, provided they are instructed and informed of the risks and benefits, especially in matters of the end of life. AD are about the respect for human autonomy²⁸; it is not a matter of randomly offering what the patient wants or not, but including what is scientifically appropriate, indicating what is proportional, adapting therapeutic interventions to the moment of life and diseases that the patient faces, without abandoning them or intervening obstinately^{2,3}. The health professionals' lack of understanding about end of life and AD can lead them to obstinate actions, indicating treatments that do not provide comfort, benefits or quality of life to patients. This type of attitude is often based on an attempt to avoid judicialization; however, it only prolongs the process of dying without providing quality of life²⁹.

This research project was conceived with the aim of evaluating whether professionals and users of a Brazilian teaching hospital located in Curitiba/PR needed instruction on AD. Thus, physicians, nurses and nursing technicians were included, as these are the professionals who deal directly with patients and whose codes of professional ethics describe the subject. However, it is emphasized that the involvement of the entire multidisciplinary team is important for quality comprehensive care and introduction of AD.

The scientific literature reports that, when health professionals are trained in end-of-life issues, they are more confident when providing care³⁰ and show less moral anguish when dealing with the many issues involved in this period, such as the AD³¹. The preparation of directives increases the patient's self-esteem and confidence in the care team, improves the physician-patient-family relationship and

the confidence of the care team, enables a more favorable resolution, and reduces conflicts with family members about treatments and therapeutic approaches^{8,29,32-34}. AD also contribute to reducing the occurrence of therapeutic obstinacy^{12,13,29,34}. However, studies observe that the main barrier to their application is the lack of knowledge of health professionals and of the population^{6,13,34}.

In this study, 38.1% of the health professionals and 8.3% of the users know some document related to patient declaration of will, and only 27.8% of the participating professionals knew about the term "advance directives" and 19.6% knew about CFM Resolution 1,995/2012¹. Among the users, only two people (4.2% of the total number of responding users) knew about AD, and one of them knew about the resolution. It is noted that, in the teaching hospital evaluated, few professionals know the directives and, therefore, few will be able to adequately instruct and serve patients in this regard.

The lack of knowledge about AD is still significant in Brazil. Mendes and collaborators²⁵ reported that only 12.9% of the students they interviewed knew about AD, despite 96.6% having received information on the subject in undergraduate classes. Of the physicians interviewed by Gomes and collaborators²⁴, only 23% knew about the AD and 10% knew about the regulation and, in the same study, only 3% of the users knew about the directives. In a study that only evaluated patients undergoing cancer treatment, 70% were unaware of AD²³.

The data from this research reaffirmed that the lack of knowledge about the instrument that enables the expression of autonomy in the final stage of life still prevails in Brazil, despite CFM Resolution 1,995/2012¹ existing for almost a decade. The health professionals' lack of knowledge about AD – as observed in this study – is especially important, as they are responsible for informing sick and vulnerable patients about the possibility of recording their will in medical records. In the absence of information provided by health professionals, especially physicians, few patients will have the opportunity to establish AD, perhaps with the support of lawyers or other agents of society, with the risk of having the document invalidated by the professionals who participate in the care.

The risk of not knowing about AD is reinforced by the fact that more than half of this study's participants – both professionals and users – indicated that the physician should initiate the conversation. If most physicians are unaware of AD, the subject will possibly not be discussed in the health care routine of the evaluated teaching hospital. Furthermore, it is believed that the attribution of responsibility to the physician may be motivated by a lack of knowledge, by the desire to receive care in situations of suffering and vulnerability, and, perhaps, by remnants of medical paternalism³⁴. In 2018, Kulicz and collaborators³⁵ reported that 95% of the interviewed medical students answered that physicians would be responsible for informing patients about AD. However, who is actually responsible for initiating the conversation is perhaps the least important aspect, but rather that end-of-life issues should be discussed more frequently, including patients, family members, and health care professionals.

Informing about AD seems to be an opportune procedure, and the findings of this research support this hypothesis. In this study, after informing the participants about the directives, almost all respondents indicated that people should register them, and 73.2% of the professionals and 58.3% of users indicated that they would think about establishing their own AD.

Most respondents, both professionals and users of the health service, answered that they would respect the items described in the AD, even when including the desire for death at home. However, more health care professionals than users would respect this option. Accepting the desire to die in one's own home requires preparation for the numerous challenges, and this was not the objective of this study. However, the question was formulated and maintained as a provocation of sorts about the respect for the items described in AD in unusual situations in the current context of end of life in Brazilian society.

Death at home depends on many factors, including the organization of the health system and the possibility of adequate control of uncomfortable symptoms. Considering actual data, this will may be at risk: more than 50% of people aged over 60 years surveyed in Belo Horizonte would prefer to die at home³⁶, but 88% of people

in the same age group and diagnosed with cancer died in hospitals in the city of São Paulo³⁷.

For death to occur at home, family members must be willing and respect this choice, which seems unlikely, according to a portion of the participants in this study. Thus, it was understood that another challenging aspect for AD are choices that may not be aligned with the will of family members, potential decision makers with health professionals when the patient is unable to express their will at the end of life.

Trust in the family members' respect for AD is another important aspect demonstrated in a similar manner among the participants. Of the professionals, 36% do not trust or do not know if they can trust in such respect, and 48% of the users responded in the same way. The possibility of decisions being made even without the agreement of family members is one of the prerogatives of AD. CFM Resolution 1,995/2012 establishes in article 2, paragraph 3, that the patient's AD *will prevail over any other non-medical opinion, including the will of family members*¹. Empathic communication and conflict resolution should be favored⁸; however, in Brazil, when dealing with issues that cannot be resolved otherwise, physicians can validate the patients' ethical will and comply with items declared in the AD. Thus, AD are corroborated as an instrument of respect for the autonomy informed and shared between patient and physician.

The interest in knowing about AD and achieving the expression of the patients' autonomy may be related to several factors other than the mere availability of information and training. Perhaps, it would be opportune for institutions to motivate, encourage and support the coping with situations of illness and end of life. It is also possible that this interest is another way of resisting or denying illness, terminality and death that is observed in today's society. Therefore, health professionals should not be the only ones held accountable for the lack of knowledge about AD. Apparently, AD remain a restricted subject, detached the reality of most Brazilians^{13,23,38}.

A study carried out in the United States showed that 44% of the surveyed population had registered AD, more frequently in the age group over 65 years³⁹. The 56% who had not written the document stated as factors for that: not knowing what it was about, how to register it, costs, and fear

or discomfort when talking about death³⁹. There are no related costs when registering AD in Brazil, unless the choice is to register them at a notary's office. Therefore, the barriers refer to knowledge, culture and will, which inevitably permeate the discomfort of conversations about death itself.

The existence of AD is not sufficient, they must be an important element to establish the relationship of trust between physician and patient. Portugal, for example, has federal regulations and an AD registry database; in theory, these would guarantee the legal "security" desired by health professionals; however, most physicians responded in a survey that they rarely or never consulted the registry database and believed that such an act would have no implications for care⁴⁰. That is, in addition to knowledge, health professionals must be willing to include ADs in their care practice.

Although we observed little knowledge among physicians, nursing professionals and users of the health system, after the explanation most participants perceived the AD as an important document, believing that people should declare their will for end-of-life treatments and answering that they would think about preparing their own AD. The discussion on declaration of will is not frequent among the Brazilian population; however, it was observed that there is openness for dialogue, and only through it the population can be made aware and informed to exercise their right to autonomy.

Limitations

The limitations of this study refer to the fact that it is a primary assessment of knowledge

using a questionnaire based on other studies, which may contain weaknesses. The participants apparently did not face the end of life at the time of the research and, therefore, the answers could be different in such a situation. Some professionals claimed to be busy and refused to participate in the study – it is unknown whether the alleged reason was real or a way to avoid the subject addressed in the research. Of the total sample, 38% were resident physicians, and therefore young and less experienced professionals. However, it should be taken into consideration that these professionals work daily in the teaching hospital's health care, and their knowledge about AD guides the health care system users' care history.

Final considerations

The data obtained in this research shows that the evaluated sample knew little about AD – only about 25% of the health professionals and 4.2% of the users of SUS in a teaching hospital knew about the directives. After being informed about AD, most participants believed that people should register them, that the conversation should be initiated by physicians, that they would respect the items described in the document of a family member and that they trust them, with no difference between professionals and users. After the questionnaire, most participants stated that they would think about registering their own AD. It is expected that this study will support the creation of strategies to disseminate knowledge about the importance of AD, not only among health professionals but for society in general.

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Participation of the authors

Úrsula Bueno do Prado Guirro and Fernanda de Souza Ferreira conceived the idea, wrote the pre-project, and submitted it for approval of the Research Ethics Committee. Úrsula Bueno do Prado Guirro also interpreted the results, wrote and revised the manuscript. Fernanda de Souza Ferreira collected data with Giovana Ferreira de Freitas Miranda and Lorena van der Vinne – who typed them – and assisted in the preliminary writing of the manuscript.

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