

Advance directives: knowledge and acceptance by health professionals

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Abstract

Using a self-administered questionnaire, this study investigated the knowledge and acceptance by health professionals of advance directives and palliative care in primary care. Of the 40 participating health professionals, most were nurses, physicians, and nursing technicians. Female professionals (77.5%) between 30 and 59 years of age (82.5%), with 10 to 19 years since graduation (45%) and married (65%) predominated in the sample. Most participants (65%) showed familiarity with the World Health Organization's guidelines on palliative care. However, over half (55%) were unaware of advance directives. Professionals showed reasonable knowledge of World Health Organization guidelines on palliative care but complete ignorance about advance directives, indicating the need for including content about palliative care and advance directives in the education and updating curricula of health professionals.

Keywords: Advance directives. Palliative care. Personal autonomy. Patient rights. Living wills.

Resumo

Diretivas antecipadas: conhecimento e aceitação de profissionais da saúde

Este estudo buscou verificar, por meio de questionário autoaplicável, o conhecimento e a aceitação dos profissionais de saúde em relação às diretivas antecipadas de vontade e aos cuidados paliativos na atenção primária. Participaram 40 profissionais de saúde, predominantemente enfermeiros, médicos e técnicos de enfermagem. Houve prevalência de participantes do sexo feminino (77,5%), com idade entre 30 e 59 anos (82,5%), tempo de formação de 10 a 19 anos (45%) e casados (65%). A maioria (65%) conhecia as diretrizes da Organização Mundial da Saúde sobre os cuidados paliativos. Entretanto, mais da metade (55%) desconhecia as diretivas antecipadas de vontade. O conhecimento das diretrizes da Organização Mundial da Saúde sobre os cuidados paliativos mostrou-se razoável, mas o desconhecimento sobre diretivas antecipadas foi elevado, do que se infere a necessidade de inclusão de conteúdos sobre cuidados paliativos e diretivas antecipadas de vontade nos currículos de formação e de atualização dos profissionais de saúde.

Palavras-chave: Diretivas antecipadas. Cuidados paliativos. Autonomia pessoal. Direitos do paciente. Testamentos quanto à vida.

Resumen

Directivas anticipadas: conocimiento y aceptación por parte de los profesionales de la salud

Este estudio buscó verificar, mediante un cuestionario autoadministrado, el conocimiento y la aceptación de los profesionales de la salud con relación a las directivas anticipadas de voluntad y a los cuidados paliativos en la atención primaria. Participaron 40 profesionales de la salud, predominantemente enfermeros, médicos y técnicos de enfermería. Hubo predominancia de participantes del sexo femenino (77,5%), con edades entre 30 y 59 años (82,5%), con un tiempo de formación de 10 a 19 años (45%) y casados (65%). La mayoría (65%) conocía las directrices de la Organización Mundial de la Salud sobre los cuidados paliativos. Sin embargo, más de la mitad (55%) desconocía las directivas anticipadas de voluntad. El conocimiento de las directrices de la Organización Mundial de la Salud sobre los cuidados paliativos resultó ser razonable, pero el desconocimiento sobre directivas anticipadas fue elevado, de lo que se infiere la necesidad de incluir contenidos sobre cuidados paliativos y directivas anticipadas de voluntad en los currículos de formación y de actualización de los profesionales de salud.

Palabras clave: Directivas anticipadas. Cuidados paliativos. Autonomía personal. Derechos del paciente. Voluntad en vida.

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With scientific advances, especially in medicine, the approach to health decline due to illness until death has changed over the last century. Many life-threatening diseases have become chronic, while others have been cured, increasing people's life expectancy¹. In certain clinical situations, however, palliative care can be proposed to those suffering from a gradual decline in health and, upon the patient's acceptance, adopted especially to relieve pain and suffering that compromise quality of life². Opting for palliative care offers a varied list of conducts that, in the impossibility of cure and admitting patient terminality, emphasize the essence of offering a better quality of life to both patients, family members and others involved in their care³.

Conversely, the paternalistic model of medical practice, in which health professionals act on their own, combined with the remarkable biotechnological advances has resulted in a significant increased use of therapeutic procedures that risk prolonging suffering for patients and their families during the process of dying⁴. When offering palliative care, health professionals must respect the autonomy of terminally ill patients, which requires involving them in the decision-making process during the end of life. Proposing treatments or their change will only occur through actions that are proportional and consistent with medical ethics and the *lex artis*. Additionally, manifestations from family members regarding decisions about care for patients who are unable to communicate could be different from those they would freely choose. In this scenario, advance directives (AD), with the designation of a health care proxy, are recommended to improve communication about the person's preferences concerning decisions about their care when unable to communicate⁵. Elaborating advance directives before presenting a significant worsening in their health condition provides patients with a mechanism to materialize their wishes regarding the treatments to be performed, maintaining their dignity⁶.

One of the foundations of the 1988 Constitution of the Federal Republic of Brazil is the dignity of the human person⁷, and when patients understand the importance of AD, they express the desire to set their own guidelines to preserve their autonomy⁸. In this regard, the Federal Council of Medicine

(CFM) Resolution 1,995/2012⁹ sought to bring legal predictability to advance directives in the professional sphere. Likewise, the Federal Council of Nursing (COFEN) advised nursing professionals to respect patients' AD¹⁰.

Following this trend, the Brazilian Ministry of Health (MS), through Resolution MS 41/2018¹¹, established that advance directives must be made available by high-complexity oncology establishments¹². Recently, Ordinance GM/MS 3,681/2024¹³ instituted AD as part of the National Policy of Palliative Care. Indeed, although not yet established in our legal system, the normative provisions, ordinances, and resolutions issued by professional councils and the MS provide legal support for applying AD in Brazil.

In terms of legislation, Senate Bill 2,986/2022¹⁴, which provides for AD on the medical care to be given to patients in specified situations, is still awaiting a rapporteur. However, Latin American countries like Colombia, Mexico, Puerto Rico, Uruguay and Argentina have legislation in this regard¹⁵.

The key research problem emerges from this context: do health professionals know about AD to care for patients in palliative care (or not) who dispose of one? As a hypothesis, it is expected that health professionals, especially physicians and nurses present good knowledge and good acceptance of AD. The other assumption was that professionals with lower time since graduation would present greater knowledge about ADs, as it is a recent topic of discussion. Thus, this research aimed to verify the knowledge and acceptance by health professionals of AD in the context of palliative care in primary care.

Methods

This is a cross-sectional, qualitative-quantitative study, conducted with primary health care professionals in the municipality of Palmas/PR, Brazil, covering family health strategies. The AD model used was initially developed by the Bioethics Committee of the Santa Terezinha University Hospital in Joaçaba, Santa Catarina, and by research conducted with undergraduate and graduate students. Based on research conducted with cancer patients and patients from the Joaçaba

Health System, AD models have been improved and made available to the population¹⁶⁻¹⁸.

Health professionals working in primary care who agreed to participate voluntarily by signing the informed consent form were included in the study. Data were collected using a semi-structured and self-administered questionnaire with questions on knowledge about advance directives and their application in palliative care. After filling in the questionnaire, an AD model was presented to participants so they could fill it in. Finally, participants were provided a second questionnaire in which they expressed their opinion on the model and whether they would recommend it. Both questionnaires were handed to the respondents in person and they were given a brief explanation of how to fill them in. Nurses, physicians, dentists, physical therapists, nursing technicians, and community health workers were included.

Data collection took place from July to August 2023, and the results were tabulated in a Microsoft Excel spreadsheet. Data were analyzed by descriptive statistics, using frequency tables and graphs to show the results. Associations between the sociodemographic variables and the questions inherent to palliative care and AD and their evaluation were verified by Chi-square test. For analysis purposes, the data were tabulated in electronic spreadsheets and subjected to statistical analysis on SPSS, version 20.0. Qualitative analysis was performed on the online tool WordClouds (www.wordclouds.com) to identify the most relevant words.

Results

Out of a population of 52, 40 health professionals (76.9%) participated in the study distributed as

follows: 13 nurses, ten physicians, nine nursing technicians, six community health workers, one nursing assistant and one pharmacist. Female professionals account for 77.5% (n=31) of the sample. Ages ranged from 30 to 59 years (82.5%; n=33). Regarding marital status, 65.0% (n=26) were married, 22.5% (n=9) were single, and 12.5% (n=5) were divorced. As for number of children, 32.5% (n=13) had one child, 27.5% (n=11) had two children, 7.5% (n=3) had three, 5% (n=2) had four and 27% (n=11) were child-free. Regarding schooling level, 32.5% (n=13) had a high school diploma, 27.5% (n=11) had a graduate degree, 22.5% (n=9) had an undergraduate degree, and 17.5% (n=7) had a master's degree.

As for the profession, 32.5% (n=13) were nurses, followed by physicians with 25% (n=10), nursing technicians with 22.5% (n=9), community health agents with 15% (n=6), nursing assistants and pharmacists, both with 2.5% (n=1). Regarding time since graduation, 45.0% (n=18) had between 10 and 19 years of training in the profession, 35% (n=9) had up to 9 years, 17.5% (n=7) had more than 20 years, and 2.55% (n=1) did not answer. All the respondents reported working in the Basic Health Unit (UBS).

When asked about their knowledge of the World Health Organization (WHO) guidelines for palliative care, 65% stated being familiar with it, of which most were women (76.92%), nursing professionals (34.62%), nursing technicians (30.77%) and physicians (26.92%) (Table 1). Regarding time since graduation, 53.85% had between 10 and 19 years of working in the profession. Chi-square test showed no association between knowledge of WHO guidelines and gender, time since graduation or schooling level ($p>0.05$). For profession, the test was borderline positive due to the greater knowledge of certain categories ($p=0.051$).

Table 1. Knowledge of WHO guidelines for palliative care (Palmas/PR, 2024)

Gender	Yes		No		p
	n	%	n	%	
Female	20	77	11	78.57	0.905 (0.0142)
Male	6	23	3	21.43	
Total	26	100	14	100.00	

continues...

Table 1. Continuation

Profession	Yes		No		p
	n	%	n	%	
Community health worker	1	3.85	5	35.71	0.051 (11.0266)
Nursing assistant	0	0.00	1	7.14	
Nurse	9	34.62	4	28.57	
Pharmacist	1	3.85	-	0.00	
Physician	7	26.92	3	21.43	
Nursing technician	8	30.77	1	7.14	
Total	26	100.00	14	100.00	
Time since graduation	Yes		No		p
	n	%	n	%	
Up to 9 years	8	30.77	6	42.86	0.293 (3.7188)
From 10 to 19 years	14	53.85	4	28.57	
20+	4	15.38	3	21.43	
Not reported	0	0.00	1	7.14	
Total	26	100.00	14	100.00	
Schooling level	Yes		No		p
	n	%	n	%	
Secondary education	9	34.62	4	28.57	0.257 (5.3121)
Complete higher education	4	15.38	5	35.71	
Graduate studies	7	26.92	4	28.57	
Master's degree	6	23.08	1	7.14	
Total	26	100.00	14	100.00	

The association test was not statistically significant ($p>0.05$) when it came to self-rating in terms of sufficient knowledge about palliative care. When asked if the approach to terminally ill patients during their undergraduate studies was sufficient, 72.5% ($n=29$) answered no (Table 2). Similarly, 87.5% ($n=35$) indicated not having continued training in palliative care. Statistical tests showed no association with sociodemographic characteristics ($p>0.05$).

When asked if they felt able to care for terminally ill patients, 52.5% ($n=21$) said yes, whereas 47.5%

($n=19$) answered no. When testing the association with professions and other sociodemographic characteristics, the result was non-significant for all ($p>0.05$).

Regarding recommending the elaboration of ADs for patients in palliative care, only 2.5% ($n=1$) answered negatively. Their justifications for recommending the instrument can be classified into three qualitative categories: 1) patient autonomy and respect for the patient's wishes; 2) aid to health professionals' conduct; 3) patient well-being.

Table 2. Knowledge of ADs during undergraduate studies and continued training (Palmas/PR, 2024)

Gender	Sufficient approach during graduate studies					Has continued training				
	Yes		No		p	Yes		No		p
	n	%	n	%		n	%	n	%	
Female	7	63.64	24	82.76	0.196 (1.672)	4	80.00	27	77.14	0.886 (0.020)
Male	4	36.36	5	17.24		1	20.00	8	22.86	
Total	11	100.0	29	100.00		5	100.0	35	100.00	

continues...

Table 2. Continuation

Profession	Sufficient approach during graduate studies					Has continued training				
	Yes		No		p	Yes		No		p
	n	%	n	%		n	%	n	%	
Community health worker	1	9.09	5	17.24	0.836 (2.090)		0.00	6	17.14	0.456 (4.678)
Nursing assistant	0	0.00	1	3.45		0	0.00	1	2.86	
Nurse	4	36.36	9	31.03		3	60.00	10	28.57	
Pharmacist	0	0.00	1	3.45		0	0.00	1	2.86	
Physician	4	36.36	6	20.69		0	0.00	10	28.57	
Nursing technician	2	18.18	7	24.14		2	40.00	7	20.00	
Total	11	100.00	29	100.00		5	100.00	35	100.00	
Time since graduation	Yes		No		p	Yes		No		p
	n	%	n	%		n	%	n	%	
	n	%	n	%		n	%	n	%	
Up to 9 years	5	45.45	9	31.03	0.095 (6.363)	1	20	13	44.83	0.846 (0.816)
From 10 to 19 years	2	18.18	16	55.17		3	60	15	51.72	
20+	4	36.36	3	10.34		1	20	6	20.69	
Not reported	0	0.00	1	3.45		0	0.00	1	3.45	
Total	11	100.00	29	100.00		5	100.00	35	100.00	
Schooling level	Yes		No		p	Yes		No		p
	n	%	n	%		n	%	n	%	
	n	%	n	%		n	%	n	%	
Secondary education	2	18.18	11	37.93	0.388 (4.132)	2	40.00	11	31.43	0.631 (2.573)
Complete higher education	3	27.27	6	20.69		0	0.00	9	25.71	
Graduate studies	5	45.45	6	20.69		2	40.00	9	25.71	
Master's degree	1	9.09	6	20.69		1	20.00	6	17.14	
Total	11	100.00	29	100.00		5	100.00	35	100.00	

Participants were asked if they had ever received a recommendation in their work environment not to adopt procedures to resuscitate terminally ill patients and, among the professions, nurses stood out with 50% responding positively. Among the other professionals, most answered no or could not indicate. The statistical test showed an association only for profession ($p < 0.05$), and was negative for gender, schooling level and time since graduation ($p > 0.05$).

When asked if they agreed with keeping terminally ill patients alive using devices, 82.5%

disagreed whereas 17.5% agreed. Agreeing participants justified their position with "Patients may react" and "I believe that everything is reversible, except death." Those who disagreed stated: "It will only prolong their suffering" (P2); "No life probability" (P3); "I believe that it would reduce family suffering" (P4); "Needless suffering" (P6); "It would only prolong the suffering of patients and family members" (P7); "Life is for living" (P10); "I would strongly disagree" (P11); "I would be taking someone's life" (P13); "I would disagree because there is no longer any brain activity, which

is compatible with a lack of life. Life has a cycle to be respected" (P17); "Death is part of life" (P19); "Life is to be lived without suffering" (P23); "In an irreversible situation, the best thing to do is to let go" (P24); "Because I believe it prolongs suffering" (P25); "Because of the costs and confidence in the current system for determining the state of death and irreversibility" (P27); "Because life is already over and would only prolong suffering" (P28); "Because it increases the suffering of family members and the patient" (P31); "I would strongly disagree, as I consider it a prolongation of pain and suffering" (P35); "It would prolong patient suffering" (P36); "It prolongs the suffering of users and their families" (P37); "I find it unjustifiable to prolong my suffering, as a patient, and that of my family" (P38); "I consider this a survival without any quality" (P39); "Because the

patient is already suffering a lot, including the family members themselves, [we must] avoid prolonging this suffering any longer" (P40); "Patients would go through a vegetative process that I don't approve, not to mention their families getting worn out, losing a bit of their life together" (P5). Wordcloud analysis highlighted the words "suffering," "life," "patient," "prolong" and "family members," denoting the participants' concern with dysthanasia.

On knowledge about ADs, 55.0% (n=22) indicated ignoring the concept (Table 3). no statistically significant difference for the participants' demographic characteristics were found ($p>0.005$). Nursing professionals and physicians, participants with 10 to 19 years since graduation and those with the highest schooling level showed higher knowledge levels.

Table 3. Knowledge about AD versus respondent characteristics (Palmas/PR, 2024)

Gender	Yes		No		p
	n	%	n	%	
Female	15	83.33	16	72.73	0.424 (0.6386)
Male	3	16.67	6	27.27	
Total	18	100.0	22	72.73	
Profession	Yes		No		p
	n	%	n	%	
Community health worker	2	11.11	4	18.18	3.7814 (0.581)
Nursing assistant	1	5.56		0.00	
Nurse	7	38.89	6	27.27	
Pharmacist	1	5.56		0.00	
Physician	4	22.22	6	27.27	
Nursing technician	3	16.67	6	27.27	
Total	18	100.00	22	100.00	
Time since graduation	Yes		No		p
	n	%	n	%	
Up to 9 years	6	33.33	8	36.36	0.738 (1.2634)
From 10 to 19 years	8	44.44	10	45.45	
20+	4	22.22	3	13.64	
Not reported	0	0.00	1	4.55	
Total	18	100.00	22	100.00	

continues...

Table 3. Continuation

Schooling level	Yes		No		p
	n	%	n	%	
Secondary education	5	27.78	8	36.36	0.631 (2.5741)
Complete higher education	4	22.22	5	22.73	
Graduate studies	4	22.22	7	31.82	
Master's degree	5	27.78	2	9.09	
Total	18	100.00	22	100.00	

When evaluating the AD model, 72.5% (n=29) considered it good whereas 27.5% considered it acceptable. No statistically significant differences were found in responses regarding the sociodemographic variables ($p>0.05$). Organ donation stood out as the most relevant item of AD (n=25, or 39.68%), followed by limiting treatment (n=21, or 33.33%) and appointing a representative (n=17, or 26.98%). Importantly, the participants could indicate more than one item as relevant. Analysis tests showed no statistically significant association with sociodemographic variables ($p>0.05$).

No participant reported having doubts about any item in the AD. When asked if they thought it was important for people to write their AD, 92.5% (n=37) said yes and 7.5% (n=3) answered no. The latter justified their position with “Everyone knows what to do or not to do” and “Only those who are in a clinical situation that justifies it.” Agreeing respondents stated: “It’s a person’s will” (P1); “Own will” (P2); “To respect the patient’s will” (P4); “So that the patient’s wishes are met, as well as contributing to the approach of health professionals towards the patient” (P9); “So that everyone’s will is carried out” (P17); “Right to choose” (P19); “Will of the Client/Patient” (P29); “I believe it would help the teams during care, maintaining patient autonomy even in situations of coma” (P35); “It helps to draw up the singular therapeutic project” (P36); “Autonomy” (P37). Wordcloud analysis highlighted the words “will” and “patient,” denoting the participants’ concern with the autonomy of patients who are unable to communicate.

All participants thought it was important for the health departments to make ADs available. When asked if they thought it was important for the National Congress to legalize ADs, only 7.5% (n=3) of respondents said no, whereas 92.5% (n=37) answered yes ($p>0.05$). Regarding the importance of ADs for professional conduct and patient autonomy, 95% (n=38) of the participants felt that they were important in both situations ($p>0.05$). As for professional conduct in the event of a treatment change requested by the patient or their representative, 60.0% (n=24) would fully comply with the requests described in the ADs or by manifestation of their representatives, whereas 40.0% (n=16) would partially comply ($p<0.05$ for schooling level only).

Only one participant had a personal AD drawn up. Regarding their intention to do so in the next five years, 62.5% (n=25) answered yes, whereas 37.5% (n=15) said no ($p>0.05$). As for agreement with the idea that each family member should have their own personal ADs, 82.5% (n=33) said yes and 17.5% (n=7) said no ($p>0.05$). Finally, regarding their personal level of acceptance of the AD model, 52.5% (n=21) considered it “acceptable,” 45.0% (n=18) rated it as “good” and 2.5% (n=1) as “poor” ($p>0.05$).

Discussion

Sample characterization of participating health professionals showed predominance of females (n=31, or 77.5%) which can be explained by the historical and cultural context since, traditionally, health care has always been performed mainly

by women, a dynamic that possibly still exerts influence today¹⁹.

Nurses were the most common in the variable “profession,” followed by physicians. Such diversity of professions in our sample allowed us to broadly analyze the knowledge and acceptance of AD and palliative care in healthcare and to identify possible professions with greater affinity with the subject.

Regarding schooling, most participants had higher education, graduate, and master’s degrees. This is because our sample consists almost entirely of professions that require higher education, corroborating evidence that the rate of professionals without such degree generally does not exceed 10%²⁰.

As for knowledge of WHO guidelines for palliative care, most responded positively. Such knowledge may have been acquired after academic training in the daily practice, a hypothesis supported by familiarity with the topic predominating among those aged 30 to 59 years and with 10 to 19 years since graduation. Knowledge about palliative care is related to the length of experience, as professionals generally did not receive adequate academic training to address patients in end-of-life situations^{21,22}. A fact reinforcing this hypothesis is that most interviewees considered the approach taken during undergraduate studies to the care of terminal patients to be deficient. Our findings corroborate other studies that pointed out a lack of disciplines addressing palliative care in undergraduate health curricula in Brazil^{23,24}.

Professionals who considered themselves able to care for terminal patients were proportionally similar to those who did not. Some health professionals feel insecure when providing care to terminally ill patients due to the uncertainties during the transition from life to death²⁵. Absence of in-depth training in palliative care can result in professionals who are less able to address problems related to pain relief, symptom control, and emotional support, both for patients and their families, at the end of life²⁶. In this regard, most disagreed with the practice of artificially

prolonging the life of terminally ill patients, especially so as not to increase their suffering.

Over half of the interviewees indicated lacking knowledge about AD, showing that despite CFM Resolution 1,995/2012⁹ having been enacted for more than a decade in Brazil and AD inclusion into the Code of Ethics of Nursing Professionals six years ago¹⁰, research participants ignored its existence. A study with health professionals about AD in a teaching hospital located in Curitiba, Paraná, Brazil, identified that knowledge was less than ideal thus corroborating our results²⁷. This is a worrying situation when considering the increasing life expectancy which generates a greater number of diagnoses involving chronic-degenerative diseases, oncological diseases, and organ failures²⁸. One strategy to encourage the knowledge and use of ADs is either creating or approving a federal law (currently, the Senate is processing Bill 2,986/2022), making available model AD by the municipal health departments to ensure access for health professionals and the general population¹⁷.

Although most participants were familiar with WHO guidelines for palliative care (65%). When asked about advance directives, this number decreased considerably: only 45.0% indicated knowledge about the topic. This suggests that few health professionals feel prepared to properly guide and welcome patients who have AD. The initial hypothesis, that nurses and physicians would show the highest levels of knowledge about AD, was confirmed. One possible justification for such is the existence of specific guidelines from the professional nursing¹⁰ and medicine councils via CFM Resolution 1,995/2012⁹. However, our hypothesis about the correlation between knowledge about AD and time since graduation was not confirmed, meaning that teaching has not yet produced effects in the analyzed sample.

Almost all (95%) recognized the importance of AD for professional conduct and patient autonomy, but the number of participants who would follow them fully was slightly lower (60.0%). Physicians exhibit greater adherence to AD due to greater

knowledge on the topic and more experience in treating chronic, terminal, and palliative care patients²⁹. Likewise, due to similar professional performance and ethical orientations, nursing professionals come second.

However, dissemination of information on the subject emerges as an opportune path and our findings support this hypothesis. Despite this disregard, after providing a model of advance directives to the participants almost all agreed that each family member should have one, but those who would fulfill them in the next five years were fewer in number. Hence the necessity to encourage teaching and academic research, as well as the creation of a national law that regulates and disseminates knowledge on AD.

As for recommending AD for palliative care patients, only one participant (2.5%) answered negatively. Respect for patient autonomy, fulfillment of patients' wishes and well-being, and featuring as a guideline for professional conduct were the main justification for recommending AD. Developing an AD constitutes an ethical action and a responsibility, as it offers patients the opportunity to make personal decisions without external interference, whether from family members, health professionals or the institution^{30,31}.

Most participants considered the AD model presented as good (72.5%), pointing out organ donation as the most relevant item. A study analyzing the knowledge of older adults about ADs in a municipality from midwestern Santa Catarina found an emphasis on designation of a representative and organ donation¹⁸. These results suggest that knowledge dissemination regarding ADs could have a positive impact on organ donation in Brazil. This is because the donation process occurs legally by family decision and not that of the potential donor. Moreover, it is common for many individuals not to express the desire to become donors which often results in family refusal to donate organs^{32,33}.

Almost all participants disagreed with the artificial prolongation of life by means of devices

in terminally ill patients. Words like "suffering," "patients," "relatives" and "prolong" were highlighted by the quantitative analysis, emphasizing what the participants want to avoid for both patients and family members. Created for this purpose, CFM Resolution 1,805/2006³⁴ authorizes, in its article 1, physicians to limit or suspend procedures and treatments that prolong the life of terminally ill patients with serious and incurable illnesses, respecting the will of the person or their legal representative. Palliative care emerges in this context as a multidisciplinary approach focused on providing symptomatic relief and improving the quality of life of patients and their families in the event of serious illness, minimizing pain, physical stress, and mental stress from diagnosis³⁵.

Most participants recommend the elaboration of an AD and its availability to the population, emphasizing words like "will" and "patient" to reflect their concern with patient autonomy. Additionally, the participants expressed the desire for the National Congress to approve the law that regulates ADs to ensure and facilitate this autonomy through the Ministry of Health's infrastructure.

Not all the interviewees would change their conduct to meet a patient's desire expressed in this document. A major barrier to AD application and use is poor knowledge on the part of health professionals and population and the lack of specific law, as corroborated by other studies^{17,27}. Our data pointed to a deficit in knowledge about ADs among the participants—in fact, only one had a personal AD. Considering that AD in Brazil do not entail costs, unless one chooses to register them in a notary's office, the barriers may be related to lack of knowledge, culture, willingness to elaborate it and factors that permeate discomfort in conversations about one's own death²⁷.

As a limitation, the use of a self-administered questionnaire may have produced bias in some information which answers could cause embarrassment. As a strength, the sample size can be mentioned, which, due to the difficulty in

engagement, was close to the ideal number and enabled statistical analyses.

Final considerations

Professionals showed reasonable knowledge of WHO guidelines for palliative care but a deficit in knowledge about advance directives. Nursing professionals and physicians, professionals with 10 to 19 years of education, and those with higher schooling levels were more knowledgeable about AD. However, statistical testing showed no differences between knowledge and the variables “profession,” “time since graduation” and “schooling.”

Results indicate that health professionals who receive sufficient information about this concept

show high acceptance of ADs and that most recommend them, especially for patients under palliative care. Hence the importance of including AD and palliative care contents in the academic curricula of health professionals, as well as regular training and dissemination of educational materials for both health professionals and the general public. The high acceptance and justifications presented are arguments for the National Congress to expedite the processing of the bill on AD, the approval of which would favor its availability to the interested population.

This study is expected to contribute to developing strategies for disseminating knowledge about the importance of AD among health professionals, legislators and Brazilian society.

References

1. Veras RP. Chronic diseases and longevity: future challenges. *Rev Bras Geriatr e Gerontol* [Internet]. 2023 [acesso 16 jan 2025];26. DOI: 10.1590/1981-22562023026.230233.en
2. Marchi LPS, Santos Neto MF, Moraes JP, Paiva CE, Paiva BSR. Influence of advance directives on reducing aggressive measures during end-of-life cancer care: a systematic review. *Palliat Support Care* [Internet]. 2021 [acesso 16 jan 2025]; 19(3):348-54. DOI: 10.1017/S1478951520000838
3. Marengo MO, Flávio DA, Silva RHA. Terminalidade de vida: bioética e humanização em saúde. *Med (Ribeirão Preto)* [Internet]. 2009 [acesso 16 jan 2025]; 42(3):350-7. Disponível: <https://tinyurl.com/k4sk8scj>
4. Scottini MA, Siqueira JE, Moritz RD. Direito dos pacientes às diretivas antecipadas de vontade. *Rev. bioét. (Impr.)* [Internet]. 2018 [acesso 16 jan 2025]; 26(3):440-50. DOI: 10.1590/1983-80422018263264
5. Ache K, Harrold J, Harris P, Dougherty M, Casarett D. Are advance directives associated with better hospice care? *J Am Geriatr Soc* [Internet]. 2014 [acesso 16 jan 2025];62(6):1091-6. DOI: 10.1111/jgs.12851
6. Lucena MA. Diretivas antecipadas de vontade em fase final de vida: reflexão à luz dos direitos humanos dos pacientes em cuidados paliativos [Internet] [dissertação]. Brasília: Universidade de Brasília; 2021 [acesso 16 jan 2025]. Disponível: <https://tinyurl.com/5n7m3u2f>
7. Brasil. Constituição da República Federativa do Brasil. *Diário Oficial da União* [Internet]. Brasília; 1988 [acesso 30 jun 2023]. Disponível: <https://tinyurl.com/28whur33>
8. Comin LT, Panka M, Beltrame V, Steffani JA, Bonamigo EL. Percepção de pacientes oncológicos sobre terminalidade de vida. *Rev. bioét. (Impr.)* [Internet]. 2017 [acesso 16 jan 2025];25(2):392-401. DOI: 10.1590/1983-80422017252199
9. Conselho Federal de Medicina. Resolução n° 1.995, de 9 de agosto de 2012. Dispõe sobre as diretivas antecipadas de vontade dos pacientes. *Diário Oficial da União* [Internet]. Brasília: 2012 [acesso 16 jan 2025]. Disponível: <https://tinyurl.com/m4ztk4m>
10. Conselho Federal dos Profissionais de Enfermagem. Resolução n° 564/2017. Código de Ética dos Profissionais de Enfermagem. *Diário Oficial da União* [Internet]. Brasília, p. 297, 2018 [acesso 16 jan 2025]. Disponível: <https://tinyurl.com/4hv7k3xs>
11. Brasil. Ministério da Saúde. Resolução n° 41, de 31 de outubro de 2018. Dispõe sobre as diretrizes para a organização dos cuidados paliativos, à luz dos cuidados continuados integrados, no âmbito Sistema

- Único de Saúde (SUS). Diário Oficial da União [Internet]. Brasília, 2018 [acesso 16 jan 2025]. Disponível: <https://tinyurl.com/3k694aub>
12. Brasil. Ministério da Saúde. Secretaria de Atenção Especializada à Saúde. Portaria SAES/MS nº 1399, de 17 de dezembro de 2019. Redefine os critérios e parâmetros referenciais para a habilitação de estabelecimentos de saúde na alta complexidade em oncologia no âmbito do SUS. Diário Oficial da União [Internet]. Brasília, p. 173, 2019 [acesso 16 jan 2025]. Disponível: <https://tinyurl.com/3h53s2nm>
 13. Brasil. Ministério da Saúde. Portaria GM nº 3.681, de 7 de maio de 2024. Institui a Política Nacional de Cuidados Paliativos – PNCP no âmbito do Sistema Único de Saúde – SUS. Diário Oficial da União [Internet]. Brasília, 2024 [acesso 16 jan 2025]. Disponível: <https://tinyurl.com/mtktxejw>
 14. Brasil. Senado Federal. Projeto de Lei nº 2986/2022. Dispõe sobre as diretivas antecipadas de vontade acerca de cuidados médicos a serem submetidos os pacientes nas situações especificadas. Diário Oficial da União [Internet]. Brasília, 2022 [acesso 16 jan 2025]. Disponível: <https://tinyurl.com/yjxcz433>
 15. Monteiro RSF, Silva Junior AG. Diretivas antecipadas de vontade: percurso histórico na América Latina. Rev. bioét. (Impr.) [Internet]. 2019 [acesso 16 jan 2025];27(1):86-97. DOI: 10.1590/1983-80422019271290
 16. O que são as Diretivas Antecipadas de Vontade? [Internet]. 2023 [acesso 16 jan 2025]. Disponível: <https://diretivasantecipadas.com.br/>
 17. Pepes CV, Pepes MV, Neuhauser J, Salort JCA, Steffani JA, Bonamigo EL. Directivas anticipadas: un instrumento de autonomía para los pacientes oncológicos. Rev. bioét. (Impr.) [Internet]. 2023 [acesso 16 jan 2025];31:1-10. DOI: 10.1590/1983-803420233471ES
 18. Vanzella GS, Souza ICD, Ferreira JC, Beltrame V, Cetolin SF, Bonamigo EL. Diretivas antecipadas de vontade na perspectiva da população idosa de um município do meio oeste catarinense. Rev Bras Geriatr e Gerontol [Internet]. 2023 [acesso 16 jan 2025];26:1-12. DOI: 10.1590/1981-22562023026.230094.pt
 19. Sousa JM, Alves ED. Competências do enfermeiro para o cuidado paliativo na atenção domiciliar. Acta Paul Enferm [Internet]. 2015 [acesso 16 jan 2025];28(3):264-9. DOI: 10.1590/1982-0194201500044
 20. Borges T, Barros F, Mielke G, Parra D, Siqueira F, Hallal P. Conhecimento de profissionais que atuam em Unidades Básicas de Saúde no Brasil sobre a associação entre inatividade física e morbidades. RBAFS [Internet]. 2018 [acesso 16 jan 2025];22(5):450-6. DOI: 10.12820/rbafs.v.22n5p450-456
 21. Ferreira JMG, Nascimento JL, Sá FC. Profissionais de saúde: um ponto de vista sobre a morte e a distanásia. Rev Bras Educ Med [Internet]. 2018 [acesso 16 jan 2025];42(3):87-96. DOI: 10.1590/1981-52712015v42n3RB20170134
 22. Smets T, Pivodic L, Piers R, Pasman HRW, Engels Y, Szczerbińska K et al. The palliative care knowledge of nursing home staff: the EU FP7 PACE cross-sectional survey in 322 nursing homes in six european countries. Palliat Med [Internet]. 2018 [acesso 16 jan 2025];32(9):1487-97. DOI: 10.1177/0269216318785295
 23. Oliveira JR, Ferreira AC, Rezende NA, Castro LP. Reflexões sobre o ensino de bioética e cuidados paliativos nas escolas médicas do estado de Minas Gerais, Brasil. Rev Bras Educ Med [Internet]. 2016 [acesso 16 jan 2025];40(3):364-73. DOI: 10.1590/1981-52712015v40n3e01632015
 24. Guimarães TM, Silva LF, Santo FHE, Moraes JRMM, Pacheco STA. Cuidado paliativo em oncologia pediátrica na formação do enfermeiro. Rev Gaúcha Enferm [Internet]. 2017 [acesso 16 jan 2025];38(1):364-73. DOI: 10.1590/1983-1447.2017.01.65409
 25. Sousa EC, Carvalho HML, Vilaça DHV, Silva LMS, Costa MMR, Borges BQOV et al. Cuidados paliativos: Importância da assistência à saúde ao paciente em fase terminal. Brazilian J Heal Rev [Internet]. 2020 [acesso 16 jan 2025];3(5):12258-66. DOI: 10.34119/bjhrv3n5-072
 26. Alves MA, Martins RD. A importância da formação em cuidados paliativos na graduação em enfermagem. Rev Enferm Atual Derme [Internet]. 2023 [acesso 16 jan 2025];97(3):1-7. DOI: 10.31011/reaid-2023-v.97-n.3-art.1961
 27. Guirro UBP, Ferreira FS, Vinne L, Miranda GFF. Conhecimento sobre diretivas antecipadas de vontade em hospital-escola. Rev. bioét. (Impr.) [Internet]. 2022 [acesso 16 jan 2025];30(1):116-25. DOI: 10.1590/1983-80422022301512PT

28. Pereira WAB, Oliveira IR, Werner F, Santos LT, Furtado PS, Brigagão RV *et al.* Aumento da expectativa de vida e crescimento populacional no Brasil e os impactos no número de pessoas vivendo com doenças crônico-degenerativas: desafios para o manejo da Doença de Alzheimer. *Res Soc Dev* [Internet]. 2023 [acesso 16 jan 2025];12(5). DOI: 10.33448/rsd-v12i5.31673
29. Arruda LMAD, Abreu KPB, Santana LBC, Sales MVDC. Variables that influence the medical decision regarding Advance Directives and their impact on end-of-life care. *Einstein (São Paulo)* [Internet]. 2019 [acesso 16 jan 2025];18:eRW4852. DOI: 10.31744/einstein_journal/2020RW4852
30. Bermejo JC, Belda RM. Testamento vital: diálogo sobre a vida, a morte e a liberdade. São Paulo: Loyola; 2015.
31. Dadalto L. Distorções acerca do testamento vital no Brasil (ou o porquê é necessário falar sobre uma declaração prévia de vontade do paciente terminal). *Rev Bioet Derecho* [Internet]. 2013 [acesso 16 jan 2025];28:61-71. DOI: 10.4321/S1886-58872013000200006
32. Okano CS, Menezes CCS, Brandão FA, Carletto VR, Souza MA. Análise do cenário nacional de transplantes no Brasil *Res Soc Dev* [Internet]. 2023 [acesso 16 jan 2025];12(9):e3112943188. DOI: 10.33448/rsd-v12i9.43188
33. Barreto BS, Santana RJB, Nogueira EC, Fernandez BO, Brito FPG. Fatores relacionados à não doação de órgãos de potenciais doadores no estado de Sergipe, Brasil. *BJHR* [Internet]. 2016 [acesso 16 jan 2025];18(3):40-8. DOI: 10.21722/rbps.v18i3.15741
34. Conselho Federal de Medicina. Resolução nº 1.805, de 28 de novembro de 2006. Na fase terminal de enfermidades graves e incuráveis é permitido ao médico limitar ou suspender procedimentos e tratamentos que prolonguem a vida do doente, garantindo-lhe os cuidados necessários para aliviar. *Diário Oficial da União* [Internet]. Brasília, p. 169, 28 nov 2006 [acesso 16 jan 2025]. Disponível: <https://tinyurl.com/yu78wa3v>
35. Crucioli RM, Cunha LP, Cardoso LC, Eduardo AMLN. Cuidados paliativos em pacientes oncológicos. *Acta Ciências e Saúde* [Internet]. 2019 [acesso 16 jan 2025];8(1):13-30. Disponível: <https://tinyurl.com/j5zj49pr>

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