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RESEARCH

Advance directives in geriatric medicine

Bruna Mota Machado Gomes[1], *Lorena Araújo Salomão*[1], *Aratti Cândido Simões*[2], *Bárbara Otoni Rebouças*[1], *Luciana Dadalto*[3], *Maira Tonidandel Barbosa*[4]

1. Faculdade de Ciências Médicas de Minas Gerais (FCMMG), Belo Horizonte/MG **2.** Fundação Educacional Lucas Machado (Feluma), Belo Horizonte/MG **3.** Faculdade Batista de Minas Gerais (FBMG), Belo Horizonte/MG **4.** Universidade Federal de Minas Gerais (UFMG), Belo Horizonte/MG, Brasil.

Abstract

Advance directives represent the decisions about medical care and treatment that a patient wishes to receive, if unable to express their will. We evaluated the knowledge of elderly caregivers in a geriatric outpatient clinic (n=66), lecturers (n=60) and medical students (n=72) regarding these directives, the intention to create the document, and the conduct during this situation. The results show that only 20% of the participants knew, or at least have an idea of, what these directives are. The majority of terminally ill patients (72%) preferred to die at home, receiving palliative care; 32% preferred dying in a hospital; and 45% agreed to be taken to an intensive care unit. Only 40% opt for this expression of will, even after explanations. More than half (56%) trust that medical teams will respect their decisions, and 83% trust their family members. It is concluded that the subject should be discussed more in society, especially in the fields of teaching and health care.

Keywords: Advance directives. Aged. Personal autonomy. Palliative care. Death.

Resumo

Diretivas antecipadas de vontade em geriatria

Diretivas antecipadas de vontade representam as decisões sobre cuidados e tratamentos que um paciente deseja receber se incapacitado de expressar sua vontade. Foi avaliado o entendimento de acompanhantes de idosos (n=66) em ambulatório geriátrico, professores (n=60) e alunos de medicina (n=72) quanto a essas diretivas, a intenção de fazer o documento e as condutas durante essa situação. Os resultados mostram que somente 20% dos participantes sabem ou ao menos têm ideia do que sejam essas diretivas. A maioria dos pacientes em estado terminal (72%) prefere falecer em casa, recebendo cuidados paliativos; 32% preferem o hospital; e 45% aceitam ser levados à terapia intensiva. Poucos optam por essa manifestação de vontade, mesmo após explicações. Mais da metade (56%) confia que equipes médicas respeitarão suas decisões, e 83% confiam em familiares. Conclui-se que o assunto deve ser mais discutido na sociedade, principalmente nas áreas de ensino e assistência à saúde.

Palavras-chave: Diretivas antecipadas. Idoso. Autonomia pessoal. Cuidados paliativos. Morte.

Resumen

Directivas anticipadas de voluntad en geriatría

Las directivas anticipadas de voluntad representan las decisiones sobre los cuidados y tratamientos que un paciente desea recibir, si estuviera incapacitado para expresar su voluntad. Se evaluó, en un ambulatorio geriátrico, el entendimiento de acompañantes de ancianos (n=66), profesores (n=60) y estudiantes de medicina (n=72) sobre estas directivas anticipadas, la intención de hacer el documento y las conductas durante esa situación. Los resultados muestran que solamente el 20% de los participantes saben o tienen alguna idea de lo que son las directivas anticipadas. La mayoría de los pacientes en estado terminal (72%) prefiere morir en la casa, recibiendo cuidados paliativos; el 32% prefiere el hospital; y el 45% acepta ser trasladado a cuidados intensivos. Pocos optan por esta manifestación de voluntad, incluso luego de las explicaciones. Más de la mitad (56%) confía en que los equipos médicos respetarán sus decisiones, y el 83% confía en sus familiares. Se concluye que el asunto debe ser más discutido en la sociedad, principalmente en las áreas de educación y cuidado de la salud.

Palabras clave: Directivas anticipadas. Anciano. Autonomía personal. Cuidados paliativos. Muerte.

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Declaram não haver conflito de interesse.

In the last decades, the advancement of medical technologies has prolonged and improved the quality of life of the population, even in the case of serious, incapacitating and progressive diseases[1]. But the increase in life expectancy also increases the questioning of the value of certain measures to sustain life[2]. In this context, the decision for artificial medical care to prolong life has been debated in several areas in Brazil, seeking effective legislation, especially by the Conselho Federal de Madicina (CFM - Brazilian Federal Council of Medicine), body responsible for supervising the performance of physicians .

By means of norms/resolutions on the advance written directives (AWD), which legitimize the will of the patient, as reported by him/her or his/her legal representatives while facing serious or irreversible diseases, the best way to care for this population is discussed.

AWDs represent the patient's willingness to undergo medical treatment through living will (LW) and the long-term mandate[3]. The LW is the document with the patient's advance wishes in a state of lucidity and full decision-making autonomy, to be evaluated when they can no longer decide for themselves; when this happens, the long-term mandate is used, which appoints someone to make decisions for him[1]. According to Dadalto, Tupinambás and Greco[3], this concept assumes that the patient has the right to refuse treatments that do not heal or alleviate symptoms, but only prolong life and suffering.

This perspective follows Thompson's line[4] when he states that AWD are instructions that the patient prepares to guide their medical care, and can be used if the attending physician determines that the patient is no longer able to make his/her own decisions. The LW is a very common type of advance directive from which the patient defines which treatments he wants to receive: cardiopulmonary resuscitation, mechanical ventilation, artificial diet, medications, intravenous fluids and others.

Even though it is a topic of great importance and recurrence in daily medical activity, in general, Brazilian health professionals have little familiarity with the subject. According to Piccini et al.[1], only one third of the physicians and medical students interviewed knew the meaning of LW. And, according to Barbosa and collaborators' pilot project survey[5] with 50 people in the geriatric outpatient clinic of the Unified Health System (SUS), almost 90% of those interviewed do not know LW or AWD. In the same survey, 92% claimed they had never talked to family members about it.

The data illustrate the Brazilian population's lack of knowledge about the subject until they are faced with a real situation in which it becomes necessary to decide on the medical treatment of a relative in the terminal phase of life[1]. To amplify this important discussion, one must reinforce the difference between the three main aspects of medical conduct in the face of palliative care: euthanasia, dysthanasia and orthothanasia.

In euthanasia, the professional, usually the physician, makes some decision that could lead to the death of the patient, in the name of releasing him from the suffering of some serious illness. However, euthanasia is prohibited by law in Brazil and contradicts professional responsibility in the ethical practice of medicine. In article 14 of the Code of Medical Ethics (CME), the physician is prohibited from practicing or indicating medical acts unnecessary or prohibited by the legislation in force in the country[6,7].

Article 29 of the same code establishes that *the physician is prohibited from participating, directly or indirectly, in the execution of the death penalty,* in accordance with the sole paragraph of article 41: *in cases of incurable and terminal illness, the physician should offer all care available without undertaking unnecessary or obstinate diagnostic or therapeutic actions, always taking into account the expressed will of the patient or, in case that is not available, that of the patient's legal representative*[7].

Dysthanasia can be understood as the prolongation of life in an artificial, futile way, in irreversible situations, with no prospect of cure or improvement[8]. The patient undergoes slow death and suffering. Pessini makes extensive digression on the term:

> *The Aurelio Dictionary of Portuguese provides the concept: "Slow, anxious death with much suffering". It is, therefore, a neologism, a new word, of Greek origin. The Greek prefix dys has the meaning of "withdrawal," so dysthanasia means exaggerated prolongation of a patient's death. The term can also be used synonymously with useless treatment. It is the medical attitude that, in order to save the life of the terminal patient, puts him in great suffering. In this conduct life itself does not extend, but the process of dying. In the European world there is talk of "therapeutic obstinacy" in the United States of "medical futility"*[9].

According to Junges et al.[10], "orthatanasia", etymologically means "right death" - ortho, "right"; thanatos, "death". It means the non-artificial postponement of death, beyond what would be only natural. The authors explain that this practice prevents unnecessary prolongation of the patient's life. From this concept, palliative medicine is conceived, which, according to the World Health Organization (WHO), *is the approach that promotes the quality of life of patients and their families in face of diseases that threaten the continuity of life, through prevention and relief of the suffering*[11]. According to article 41 of CFM Resolution 1931/2009, *the physician is forbidden to shorten the life of the patient, despite the request of the patient or his/her legal representative*[7].

Currently, the country follows the worldwide trend of autonomy expression, which makes this discussion notorious. Therefore, in order to make decisions in uncertain and delicate moments like death or life-prolonging treatments, the Brazilian population needs to know the subject better.

Faced with the concepts presented and believing that death must be part of the routine of the population and of the health system in the country, research was conducted at a Brazilian medical school. Even after the resolution of 2012 of the CFM[12] that deals with the AWD of the patients, it is believed that the current knowledge about the subject is still very incipient in the groups evaluated: companions/relatives of elderly outpatients in geriatrics, medical students and medical professors of the same school. Significant differences were found in the responses among the three groups on knowledge, experience with desire to perform terminal procedures, and on LW/AWD itself.

Objectives

To evaluate the level of knowledge and intentions related to the AWD of companions of the elderly attended at a reference outpatient clinic in a higher education institution geriatrics, as well as a group of teachers and medical students.

As secondary objective, we investigated the percent of respondents from the three groups that have theoretical knowledge about AWD, seeking to know the intention to previously report the wishes of the patient. In addition, the differences in responses about the medical treatment proposed by the interviewee for himself and his relative were analyzed, and the degree of confidence of the interviewees regarding the medical teams and close relatives about the respect for their decisions was evaluated.

With these results, we intend to provide data on the participants' understanding of the AWD, stimulating new studies and reflections that contribute to increase knowledge and debate on the topic.

Methods

Type of study

A cross-sectional study was conducted at the facilities of the Faculdade de Ciências Médicas de Minas Gerais (FCMMG - School of Medical Sciences of Minas Gerais) about the understanding of three different groups of participants regarding the AWD.

Participants

The inclusion criteria of the study were: 1) companions of elderly patients with chronic disease attended at the geriatric outpatient clinic of the FCMMG; 2) medical professors of medical school in the same faculty; and 3) students from years 4 to 6 of the institution.

Sample size calculation was based on the method of Fleiss, Levin and Paik 13 for finite populations. Estimation accuracy was used with 80% sample power, based on the proportions of the groups considered knowledgeable in the subject (20% of the students, 40% of the teachers and 12% of the companions). The *Power Analysis and Sample Size (PASS)* software[14], version 12, 2013 was used.

Calculated sample sizes: companions (n = 76), for 0.1 precision using the bilateral binomial test; medical students (n = 72), for 0.12 precision; teachers (n = 60) with 0.15 precision. The level of statistical significance was 0.05 ($p < 0.05$).

Procedures

The questionnaires were applied by three FCMMG medical students in years 4, 5 and 6 and by a geriatric resident at the outpatient clinic between April and September 2016. The questions were read, and the answers were filled individually by the interviewer, ensuring that assistance or consultation were not provided to the interviewee.

At each approach, the researchers presented and explained the objectives and reasons for the research, providing the free informed consent form (FICF) to the participant. The interviews were consecutive and random, in a waiting room or office, to guarantee the privacy of the participants, without external influence.

Three different questionnaires were elaborated, each with 17 questions, with the six initial questions focused on the sociodemographic profile. In the companion questionnaire, there were questions about their kinship with the patient attended at the outpatient clinic and knowledge about their diagnosis.

In the other questions, all were about the AWD: about the knowledge and desire to have the document, behaviors that the interviewees would adopt with their families and with themselves in a situation of irreversible disease and end of life. We also investigated the degree of confidence of respondents on their families and medical staff regarding the respect of all patients' AWDs.

Descriptive and comparative analyzes were performed in the three groups separately, listing all variables. Absolute and relative frequencies were used for the categorical variables and the mean and standard deviation for the quantitative variables. For the comparisons between two categorical variables, we chose the chi-square test [15] and, when necessary, Fisher's exact test (when the observed frequency of any category in the contingency table was less than 5) [15].

In order to compare the age of the interviewees with the teachers' training time, the Kruskal-Wallis test [16] was applied; and for the multiple comparisons, the Nemenyi test [17] was used. The software used in these cases was R version 3.2.4.

Results

Total participants

Of the 199 interviewees, 73 (37%) were medical students, 66 (33%) were companions of elderly patients in a geriatrics outpatient clinic, and 60 (30%) were medical teachers from the school. In the three groups, 53% of the interviewees were women and 47% were men, with a mean age of 41.5 years (± 16.4).

When asked what the AWDs are, 78% said they did not know, 12% knew the meaning, and 10% said they had an idea of the concept. Only 8% of respondents were aware of the CFM norm that regulates the AWD for physicians. After being presented to the official concept of Resolution CFM 1,995/2012 [12] and to the current situation and importance of the theme in Brazil, 23% of the participants stated they knew someone who has already used or already talked about the subject. Among those interviewed, 66% think that religion can interfere with the patient's decision, and 40% have shown, from the better knowledge of the subject, an interest in making an AWD document.

As to the conduct towards irreversible disease and terminal phase of life, 80% would accept to take care of relative at home, if there were resources for comfort and relief; 13% preferred the hospital and 7% did not know how to respond. In the case of the patient being the interviewee himself, 69% preferred to die at home, 17% in the hospital and 14% did not know what to answer. In addition, 46% would accept to be admitted to an intensive care unit (ICU) at the end of life, while 38% would not; and the remaining ones did not know what to answer. When asked about confidence in their AWD compliance, 84% have confidence on family members, and 58% have confidence on medical staff.

Table 1. Variables and participant questionnaire (n=199)

Variable		n	%
Group	Companion	66	33%
	Student	73	37%
	Teacher	60	30%
Sex	Female	105	53%
	Male	94	47%
Religion	Catholic	114	57%
	Spiritist	12	6%
	Evangelical	26	13%
	Other	3	2%
	No religion	44	22%
Do you know what the AWD are?	No	155	78%
	Yes	23	12%
	I have some idea	21	10%

continues...

Table 1. Continuation

Variable		n	%
Do you know of any law in Brazil regulating the AWD?	No	182	92%
	Yes	16	8%
Has your relative talked to you someone else about medical treatments when he/she is no longer conscious or with a severe disease?	No	152	76%
	Yes	46	23%
	I don't know	1	1%
Do you think religion may interfere with these decisions?	No	58	29%
	Yes	131	66%
	I don't know	10	5%
Do you think of writing an AWD?	No	73	37%
	Yes	79	40%
	I don't know	47	23%
If your family member asks to die at home, will you accept this or do you prefer the hospital?	No, I prefer to care in the hospital	25	13%
	Yes, I accept to care at home	159	80%
	I don't know	15	7%
If you are terminally ill, do you prefer to be treated at home or at the hospital?	I prefer to die at the hospital	33	17%
	I prefer to die ate home	138	69%
	I don't know	28	14%
Do you accept to stay in an ICU at the end of your life?	No	76	38%
	Yes	91	46%
	I don't know	32	16%
Do you believe your family would respect your decision?	No	18	9%
	Yes	167	84%
	I don't know	14	7%
Do you believe the medical teams would respect your decision?	No	41	20%
	Yes	115	58%
	I don't know	43	22%
Age	(Mean±SD)	41,5	16,4

AWD: advance written directives; ICU: intensive care unit; SD: standard deviation

Interviewed physicians

Among the teachers, 85% were men and 15% women, with a mean age of 52.9 years, and men time since graduation 28.1 years. When asked what the AWDs are, 77% said they did not know, 13% had an idea and 10% said they did. The same 10% knew the Brazilian norm that regulates the AWD for physicians, and they knew that there is no legislation regarding the entire population so far. After presenting the definitions of Resolution CFM 1,995/2012 [12], 27% of the physicians answered that they know someone who has already used AWD. In this group, 88% believe that religion can interfere with decisions, and 43% want to document with AWD.

As to the conduct when facing irreversible terminal illness in the terminal phase of life, 95% would accept to take care of relatives at home, if there were comfort and relief resources, 3% did not know how and 2% preferred the hospital. In the hypothesis that the patient is the very interviewee, 78% prefer to die at home, 13% did not know how and 8% prefer the hospital. In addition, 53% would not accept to stay at an ICU at the end of life, while 40% would; the remaining did not know what to answer.

When asked about confidence in their AWD being fulfilled, 93% have confidence in family members and 57% have confidence in the medical staff.

Medical students

The mean age of the students was 24.7 years, 66% being women and 34% men. When asked about AWD, 62% did not know about it, 20% did, 18% had

Research

some idea of the concept, and 12% knew about the existence of a norm in Brazil that regulated them. After presenting the official concept of the Resolution of CFM[12], 96% think that religion can interfere in this type of decision, and 56% intend to have an AWD.

Regarding the conduct of severe end-stage illness, 93% would accept care of relatives at home, if comfort and relief were available, 3% preferred the hospital, and 4% did not know how to respond. If the patient were the interviewee, 70% would prefer to die at home, 16% do not know what to answer and 14% prefer to die in the hospital; 42% would not accept to stay at an ICU at the end of life, while 32% would accept it. The remaining did not know what to answer.

When asked about confidence in their AWD being fulfilled, 71% have confidence in family members, and 47% have confidence in the medical staff.

Companions of elderly patients

In this group, 73% are women and 27% are men, with a mean age of 49.8 years. In relation to kinship, 64% are sons/daughters, 12% are spouses, 6% are sisters, 6% are grandchildren, 5% are brothers/sisters-in-law, 5% are sons/daughters-in-law, 1% are nephews/nieces, and 1% are caregivers. About AWDs, only 3% of respondents knew them, and only 2% knew about the norm that regulates them in Brazil. After being introduced to the concept, 30% answered that the family member (ambulatory patient) has already talked about the treatment when he/she can no longer decide. Only 12 percent of the respondents in this group think religion can interfere with decision-making, and 18 percent are interested in using an AWD.

As to the conduct when facing severe terminal disease, 52% answered that they accept to take care of relatives at home if there are comfort and relief resources, 33% prefer the hospital and 15% did not know how to respond. If the patient is the interviewee himself, 61% prefer to die at home, 27% prefer to die in the hospital and 12% do not know how. In this group, 67% would accept to stay in ICU at the end of life, 20% would not accept and 13% did not know.

Concerning their confidence in their AWD being fulfilled, 89% of respondents said they had confidence in family members, and 71% had confidence in the medical staff. Regarding the main diagnosis of the elderly, 90.9% of the companions claimed to know it: 47% claimed dementia; 45.5%, Alzheimer; 21.2%, Parkinson's disease; and 10.6%, depression - the four most reported diseases in this type of study.

Comparative analysis

The main question of this study - "Do you know what the AWDs are?" Was crossed between the groups of interviewees (p = 0.000), which allowed the following conclusion: the companions were the ones that knew the least about AWD (3%); students were the ones who knew the most (21%); and teachers were between the two groups (10%).

The questions "Do you know what the AWD are?" And "Do you know any law in Brazil regulating the AWD?" Were compared with the age of the interviewees, and a significant difference (p = 0.007) was observed in this question: the ones who did not know were on average older than those who had only some idea on the subject.

Crossing the variables, there was a significant association in the question "Have your relative talked to you someone else about medical treatments when he/she is no longer conscious or has a severe disease?" The students were the group with whom the family members least talked about, and the companions, the most consulted (p = 0.039). Faced with the question "Do you think religion can interfere with these life decisions?", Students and teachers agreed more than companions (p = 0.000).

The question "do you think about using AWD?" Shows that students agreed most, followed by teachers/physicians; and most of the elderly caregivers do not wish to make use of this right. The data reveal that the difference between companions and students and teachers was significant (p = 0.000). The question, "If your family member asks to die at home, will you accept this or do you prefer the hospital?" Indicates that students and teachers/physicians accept to take care of the patient at home, while companions prefer the hospital (p = 0.000). Faced with the idea of remaining in ICU at the end of life, teachers were generally reluctant, and also most of the students; unlike the companions, which has a significant difference (p = 0.000).

The expectation of fulfillment of the AWD by family members was positive in all groups: teachers were the ones who had the highest expectation (93%), followed by companions (89%) and students (71%) (p = 0.000). On the other hand, confidence in the medical teams had some differences (p = 0.024): the students relied less (47% said "yes") or did not know how to respond; 57% of teachers were also positive, and the companions were the most optimistic (71%).

The intention to consider AWD also brought pertinent information: those interviewed who do not want to use them prefer to take care of the family member in the hospital; those who want or do not know, usually take care of the family member at home. Those who are more positive about the idea prefer not to go into the ICU at the end of their lives, while the more reluctant would accept this.

Doubts about the best place to care for terminally ill patients reveal a significant association (p = 0.000): those who choose to die in the hospital hospital, whereas those who accept to die at home prefer to take care of him/her at home; and those who prefer care at home do not want to be admitted to ICU, and vice versa. In addition, respondents who do not trust their family members to respect their end-of-life decisions also do not trust medical staff, while the more confident they believe in both parties (p = 0.037).

The variables were cross-checked with answers about the respondents' religion, and there was no significant association (p > 0.05). Those who claimed to have religion were divided into Catholics, evangelicals, spiritists or others, separated from those who claim to have no religion, but these data did not interfere with the research.

Table 2. Comparisons performed among the groups

Questions	Answers	Companion		Student		Teacher		*p*-value
		n	%	n	%	n	%	
Do you know what the AWD are?	No	64	97	45	62	46	77	0.000
	Yes	2	3	15	20	6	10	
	Has some idea	0	0	13	18	8	13	
Do you know of any law in Brazil regulating the AWD?	No	65	98	64	88	53	90	0.031
	Yes	1	2	9	12	6	10	
Has your relative talked to you someone else??	No	45	68	63	86	44	73	0.039
	Yes	20	30	10	14	16	27	
	I don't know	1	2	0	0	0	0	
Do you think religion may interfere with these decisions?	No	52	79	2	3	4	7	0.000
	Yes	8	12	70	96	53	88	
	I don't know	6	9	1	1	3	5	
Do you think of writing an AWD?	No	44	67	8	11	21	35	0.000
	Yes	12	18	41	56	26	43	
	I don't know	10	15	24	33	13	22	
If your family member asks to die at home, will you accept this or do you prefer the hospital?	No, I prefer to care in the hospital	22	33	2	3	1	2	0.000
	Yes, I accept to care at home	34	52	68	93	57	95	
	I don't know	10	15	3	4	2	3	
If you are terminally ill, do you prefer to be treated at home or at the hospital?	No, I prefer to die at the hospital	18	27	10	14	5	9	0.054
	Yes, I accept to die ate home	40	61	51	70	47	78	
	I don't know	8	12	12	16	8	13	
Do you accept to stay in an ICU at the end of your life?	No	13	20	31	42	32	53	0.000
	Yes	44	66	23	32	24	40	
	I don't know	9	14	19	26	4	7	
Do you trust your family will respect your decision at the end of life?	No	4	6	14	19	0	0	0.000
	Yes	59	89	52	71	56	93	
	I don't know	3	5	7	10	4	7	
Do you have confidence in medical teams in general to respect your decision at the end of life?	No	8	12	17	23	16	27	0.024
	Yes	47	71	34	47	34	57	
	I don't know	11	17	22	30	10	16	

AWD: advance written directives; ICU: intensive care unit.

Table 3. Comparison among terminality questions

Variables		No (hospital)		Yes (home)		I don't know		*p*-value
Do you accept to stay in an ICU at the end of your life?	No	7	21%	66	48%	3	11%	0.000
	Yes	20	61%	53	38%	18	64%	
	I don't know	6	18%	19	14%	7	25%	
Do you believe your family members will respect your decisions at the end of your life?	No	4	12%	11	8%	3	11%	0.866
	Yes	27	82%	116	84%	24	86%	
	I don't know	2	6%	11	8%	1	3%	
Do you believe medical teams will respect your decisions at the end of your life?	No	7	21%	27	20%	7	25%	0.838
	Yes	17	52%	82	59%	16	57%	
	I don't know	9	27%	29	21%	5	18%	

Table 4. "Do you trust your family will respect you decision at the end of life?"

Variables		No		Yes		I don't know		*p*-value
Do you have confidence in medical teams in general to respect your decision at the end of life?	No	8	44%	32	19%	1	7%	0.037
	Yes	7	39%	101	60%	7	50%	
	I don't know	3	17%	34	20%	6	43%	

Discussion

In Brazil, because it is a very current issue, there is little research that addresses AWD and perceptions of health professionals and society. In a study carried out with a group of physicians, lawyers, medical and law students (with 209 participants) on LW, 29.2% of the interviewees knew the concept fully. Among those interviewed, 87.6% would opt for orthatanasia facing a patient in the terminal phase of life, not considering the possibility of performing the LW. If an LW were used, the option for orthothanasia would be reduced to 35.9%, while compliance with the patient's LW was indicated by 60.8% of the interviewees[1].

Another study of 100 primary care physicians, intensive care physicians, emergency physicians, and other specialties found the convenience of recording the patients' previous wishes through the AWD, and that doctors would respect them, with a score of 7.68 to 8.26 on a scale of zero to 10. Participants in the study recognize this statement as a useful tool for making decisions, with relevance assessment at 7.57 (between zero and 10). These results, although limited as a sample, signal the acceptance of patients' AWD by physicians[18].

An investigation with physicians found a perception that the resolution on the AWD satisfactorily regulated the role of professionals in its elaboration. The study shows that interviewees feel the need not to be passive in this process, providing help and offering information to the patient to prepare the document, in order to legitimize their autonomy[3].

Recently, a qualitative study with 36 residents in a public hospital showed the importance of the institute and the legal regulation of the subject, as well as the need for new studies that prove the reality of LW in Brazil[19].

Another evaluation, with 110 patients, found that knowledge about LW reached 0.13 points (from 0 to 10) among patients, increasing to 9.56 the intention to elaborate AWD after presenting its meaning, with less tendency to elaborate it among patients from 21 to 30 years of age, when compared to those of other age groups[20].

Finally, a survey of 100 oncology patients showed that 85% of them were unaware of the LW / AWD and, after clarification on the subject, 62% would agree to elaborate the document for themselves[21].

It can be observed that the research presented here is similar to previous studies, demonstrating a low level of knowledge about AWD and LW among the three groups evaluated: medical teachers, students from the 4th to 6th year of medicine and companions of elderly people attending a university geriatric outpatient clinic, the latter group being considerably less knowledgeable.

It is noted that even among physicians there is still a great deal of ignorance about the subject, which shows that the resolution of the CFM can not yet be considered effective even after four years of publication since not even its main recipients know the subject matter, possibly due to the lack of disclosure and update on the precepts that govern the medical work. On the other hand, one realizes that, even without knowing the name, most of them want the AWD, that is, the refusal of futile care and treatment for themselves and their patients and their families.

The results show that students have more knowledge about AWD than teachers, possibly because it is a very current subject, discussed in some medical disciplines that the physicians did not have access to in their medical school, especially those that do not work with patients with serious diseases and in terminal state. The curricular matrix of the medical course where the research was performed has obligatory ethics and bioethics disciplines that discuss the subject, in addition to the Internship in Health of the Elderly, which brings students closer to geriatrics and issues related to death.

Low AWD adherence is often associated with to the country's culture, the lack of the habit of talking about finitude. It turns out that as doctors are the professionals who deal with the inexorability of death since their academic years, it was expected that they had more interest in elaborating their AWD, but the research showed that even among them this will is still little.

This reality is related to the current attitudes of patients and relatives, demonstrated in several studies [19,21], and will affect the future of the AWD in Brazil, because if the physicians do not know the subject, they will not be able to inform the patients of this right nor to fulfill the desires listed in the document. And although medical students who know AWD and its regulation wish to elaborate them, no Brazilian studies with similar questions were found, which made any comparison impossible.

The responses of the companions of the elderly demonstrate the population's lack of knowledge about the subject, since 97% say they do not know about AWD nor its regulation in the country. Very similar results were found in another Brazilian study with 110 patients, which found that knowledge about LW reached only 0.13 points (from 0 to 10). Interestingly, in the study cited, and also in this research, there was an important increase in the intention of elaborating an AWD by non-medical participants after knowing its meaning [20]. This fact reinforces the need to adopt informative practices for the population.

It is important to emphasize that, as predicted at the beginning of the study, the knowledge of each group tends to be different, because the study deals with a resolution that rules the conduct of professionals, not patients. In this way, professionals should know the document, while patients and family members do not have this obligation.

The questions about termination conversations and end-of-life decisions with family members show that students are the least likely to talk with family members, and elderly caregivers are the most sought after, with a significant difference between groups. It is possible to justify this result because people tend to talk more about the end of life when they are already sick or when they are aging. As the students are younger, they probably did not experience sickness in the family or the death of family members.

Students and teachers agree more with the possibility of religion interfering in the AWD decision, while companions tend to disagree. It is interesting to note that physicians and students, who often deal with decision-making conflicts, fully affirm the influence of religion on decision-making, possibly because they have experienced similar situations in clinical practice. Companions, as they perceive the question from the individual perspective, tend to consider their own relationship to the religion or belief they profess.

We found a significant association with the question "do you think of elaborating an AWD?": Students are the most likely to have an AWD, followed by teachers. The companions, for the most part, showed no interest. Here it seems clear that companions were in an unfavorable situation since they were accompanying a sick person, so thinking of wishes about their own end was not comfortable at the time. Doctors and students tend to do their AWDs because they deal with the end of life daily.

Students and physicians, faced with the question "if your family member asks to die at home, will you accept this or do you prefer the hospital?", prefer to take care of the family member at home, while companions tend to choose the hospital. Companions place more trust in the hospital possibly because they believe there is more structure than at home, and so they feel more secure. physicians and students prefer home care because they know the negatives of hospital care.

Permanence in ICU at the end of life was rejected by teachers in general, followed by students, but the companions would accept. This difference can be attributed to the lack of information about the ICU, where patients remain alone and often under invasive procedures (breathing apparatus, artificial feeding and hydration, probes or ostomies, usually under sedation and receiving personal hygiene in their own bed). As physicians and students experience death in intensive care patients, it is easier to refuse, as they have than knowledge about the subject.

Trust in medical staff was significantly more marked by companions. This is probably due to the way in which the family-medical relationship is built, because the vulnerability of the companions often places them in a passive and subservient position to the doctor's decisions as the holder of the knowledge. It mus also be considered that companions have little decision power in the ICU and can be withdrawn if the professionals consider their presence inconvenient. This prerogative tends to make companions more submissive and agreeable.

Despite having a secondary position in intensive care units (ICUs), the family plays an indispensable role in palliative care, mainly because it assumes several responsibilities in therapeutic efforts. *It is important to keep the patient and the family informed about the situation and evolution of the disease, considering that only with the interaction of the multiprofessional team, patient and family, it will be possible to establish an action facing the patient's situation, avoiding resentment or heartache because some action has or has not been taken. Therefore, the inclusion of the AWD, with the appointment of a representative capable of responding to the end-of-life patient, is an option so that their wishes are respected by family members and medical teams. In this way, the LW, containing AWD, consists in the possibility of avoiding or reducing ethical and bioethical dilemmas between physician-patient-relatives in extreme situations* [22].

However, research performed in the hospital environment pointed out that physicians have difficulty following the patient's desire in the LW when the family is contrary to it, which demonstrates the need for greater communication on the subject between the team, patient and family, otherwise, new dilemmas may arise [23].

In this study, respondents wishing to have an AWD do not wish to remain in ICU, and vice versa. This is because the AWD are considered more important by those who prefer to refuse excessive, prolonged and futile procedures, thus avoiding dysthanasia. Likewise, anyone who accepts taking care of family members at home also prefers to die at home when their time comes. It is noticed that the interviewees tend to wish for themselves the same fate as their relative, which denotes an interesting and coherent association between the answers.

The lack of harmony between health professionals, patients and family members (or caregivers) can lengthen medical intervention indefinitely and prolong life at any cost, causing ethical and moral problems among all involved. Thus, AWDs are considered an important means of extending the autonomy of patients to situations in which they are unable to exercise it.

Final considerations

Although Resolution CFM 1995 [12] was published in August 2012, we realized that it is still unknown by a part of the physicians. Perhaps that is why a large part of the Brazilian population does not know about it either, being deprived of its science, guaranteed by law, to define in advance the options and limits of treatment that they would like to receive at the end of life. This survey showed that less than a quarter of respondents know or have an idea of what AWDs are.

Despite the low level of knowledge, 40% of the interviewees demonstrated their intention to register AWD, most of them being students to whom the concept was presented. This increase allows us to infer that knowledge helps in the decision making by the people, thus more dissemination and discussion of the subject are necessary in Brazil.

In order to encourage reflection and discussion on the document, we suggest further dissemination by CFM and regional councils, promoting events, forums, seminars and lectures for people with chronic diseases and societies and medical associations. It is also important that there is a law on AWD in Brazil, so that health professionals have legal certainty in complying with the wishes of the patient expressed in the document.

We found that the diagnosis of the relative, religion of the respondents, degree of kinship and medical specialty were not related to the knowledge of the subject or to the interviewee's decision to register and AWD. It is important to note the coherence between those who would like to be cared for at home and would take care of the terminal relative at home, since these people also do not want to stay in hospitals or bring relatives to this environment, contrary to the expressed will of the patient.

For this discussion to take place, we conclude that it is necessary to carry out more studies in Brazil that clarify the complexity of the topic and contribute to broaden the knowledge of the population (both medical and non-medical, and health professionals in general) on such an important topic for allowing several opportunities for treatment in the terminality of life. New studies may contribute to a broader proposal that establishes a culture that faces the process of death and dying in a more constructive way so that dignified death is not just a concept but a reality.

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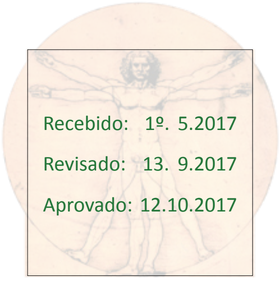
Correspondência

Maira Tonidandel Barbosa – Rua Espírito Santo, 1.996, apt. 1.001, Bairro de Lourdes CEP 30160-032. Belo Horizonte/MG, Brasil.

Bruna Mota Machado Gomes – Graduanda – brunamot@gmail.com
Lorena Araújo Salomão – Graduanda – lorenacatizani@hotmail.com
Aratti Cândido Simões – Pós-graduando – aratti.med@gmail.com
Bárbara Otoni Rebouças – Graduanda – barbara.o.reboucas@gmail.com
Luciana Dadalto – Doutora – lucianadadalto@uol.com.br
Maira Tonidandel Barbosa – Doutora – maira.tb@terra.com.br

Participation of the authors

Bruna Mota Machado Gomes and Luciana Dadalto prepared the questionnaires, reviewed the theme, analyzed the results and drafted the article. Lorena Araújo Salomão, Aratti Cândido Simões and Bárbara Otoni Rebouças participated in the training of the questionnaires and their application to the interviewees. Maira Tonidandel Barbosa contributed to the preparation of the study and the questionnaires, training of the team, evaluation of the results, statistical analysis and writing of the article, guiding the study in a general way.



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