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Advance directives in the perspective of the older adults of a municipality in the Midwest of Santa Catarina

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Abstract

Objective: To analyze the knowledge of older individuals in a municipality in the Midwestern region of Santa Catarina regarding the development of Advance Directives, their preferences regarding the available models, and the selection of a representative to make decisions on their behalf. *Method:* Cross-sectional study carried out by providing participants with two models of Advance Directives were made available to the participants for completion and applied a questionnaire on knowledge, acceptance, and evaluation of the device. *Results:* There were 85.63% of the participants who were unaware of the Advance Directives, 98.13% who were unaware of document models, 100% who considered model 1, more complete, to be good or acceptable, and 66.88% who indicated an adult child as its representative. When asked about the importance of preparing, making available to the population, and passing a law that regulates this right, the participants were assertive respectively by 91.88%, 91.25% and 91.25%. *Conclusion:* Most older people were unaware of the AD models, but mentioned model 1, considering it good or acceptable. Most had no difficulties in understanding and recognized the importance of preparing and making AD available to the population, as well as the need for a law to regulate this right. There was a high proportion of participants indicating an adult child as a legal representative, emphasizing the importance of involving the family in this process. These results highlight the need to make older people aware of AD and provide clear and comprehensive models.

Keywords: Advance Directives. Bioethics. Personal Autonomy. Aged rights.

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INTRODUCTION

The patient's dignity is supported by the exercise of their autonomy, a right guaranteed by the Universal Declaration on Bioethics and Human Rights[1], the Charter of Rights of Health Users[2] and the Code of Medical Ethics[3]. The autonomy of a person capable of communicating is exercised through Free and Informed Consent and, if incapable, through their Advance Directives (AD). In Brazil, ADs were introduced by Resolution of the Federal Council of Medicine (CFM) Nº. 1995/2012[4]. However, the Statute of Older People (Law 10.741/2003), in its article 17, guarantees older people the “right to choose the treatment they consider more favorable”[5]. All rights are based on articles 1 and 5 of the Federal Constitution[6].

The Ministry of Health established AD as guidelines for patients in palliative care through Resolution n.º 41/2018[7] and Ordinance SAES/MS n.º 1.399/2019[8]. However, no information was found about the availability of a model that facilitates its preparation by patients. However, until the end of 2022, a Bill (PLS n.º 149/2018)[9] with the purpose of regulating the AD[10], however, it was archived at the end of the 2022 legislature.

The United States was the first country to adopt AD in Federal Law, through the PSDA (*Patient Self-Determination Act*)[11]; in Europe, it started with Spain, through Law n.º 41/2002, followed by 15 other countries, such as France, Germany, Portugal and Italy[12]. In Latin America, countries such as Puerto Rico, Argentina, Mexico, Uruguay and Colombia have approved a federal law on AD[11].

The existence of a law on AD drives its development, as shown by a study carried out in Germany with more than 500 hematological and oncological patients, in which the majority only elaborated AD after the legal provision[13]. In Spain, by January 2023, 8.68 out of every 1,000 inhabitants had registered their AD in the National Registry[14].

In Brazil, there are two distinct models of AD. The first presents significant similarities with the one used in the present research, although it has a slightly different structure for entering data and offers less personalized options for the care of specific diseases[15]. On the other hand, the second model presents a less didactic text to fill in and has some important complications, such as the requirement of five witnesses and the need for registration at a notary, which makes its application on a large scale unfeasible[16].

When death is seen as a failure and even professional incompetence, the care process can drag on for longer than necessary, leading to dysthanasia[17]. Although individuals are marked by the temporality of life, the idea of finitude is fought against, an aspect that makes it difficult to approach AD in our country[18].

In this context, several questions emerge: what is the level of familiarity of the older people with AD? After acquiring knowledge about the AD, what is the relevance attributed to its elaboration? Which AD model is preferred? What are the difficulties faced in applying and understanding the available models? Which individual will be selected as a legal representative to ensure the autonomy of the older people?

Research with this category of people, especially the older people who are likely to need instruments to maintain their autonomy, is justified with the aim of developing an AD model that is as appropriate and understandable as possible. Thus, the objectives of the present research were to analyze the knowledge of the older people in a municipality in the midwest of Santa Catarina on the elaboration of AD, their preference and their difficulties in relation to the filling models and the choice of the representative who will replace them in the decision making.

METHOD

This is a descriptive and cross-sectional study with a quantitative approach, and of a regional nature, conducted through the application of a specific questionnaire and subsequent completion of two AD models, by older people in the city of Joaçaba - SC. The main objective of the questionnaire was to collect sociodemographic data and verify these people's knowledge about AD. Subsequently, the participants completed two AD models: a complete one (model 1) and an abbreviated one (model 2).

For this study, patients assisted in Health Strategies of the Unified Health System were included; patients from the Oncology Service of the University Hospital Santa Terezinha; and seniors who attended the University of the Third Age (UNITI), within the scope of the University of the West of Santa Catarina (UNOESC - Joaçaba).

In the Health Strategies, oncology service and UNITI, data collection was carried out by the authors and, at the homes, by the Health Agents, from March to September 2022. Before the field interviews, all researchers went through a guidance and training process provided by project coordinators.

For the sample calculation, a population of 5,865 older people in the city was considered[19]. In this calculation, a 90% reliability index and a 5% margin of error were used, estimating the need to include 169 participants. At the end, valid responses were obtained from 160 participants aged 60 years or older[3]. In addition to the inclusion criteria regarding age, the older people had to be lucid, capable of understanding and answering the questions presented to them. As an exclusion criterion, filling out the questionnaire was observed, in which incomplete questionnaires were excluded.

The objectives of the study were explained to each interviewee and the Free and Informed Consent Form (ICF) was presented, which is an integral part of the research protocol submitted to the Committee for Ethics in Research with Human Beings – CEP of UNOESC, approved under opinion n. 4,868,841. After explaining the purpose of the study, participants were asked to complete a questionnaire consisting of two parts. The first part included four questions about sociodemographic data, such as gender, age, education and profession. The second part consisted of two specific questions: one about knowledge about AD and the other about familiarity with existing AD models. For each participant who showed lack of knowledge, explanations about the AD were provided, followed by the presentation of two AD models, to which they should respond. Then, the participants were directed to a questionnaire with 12 specific questions, addressing their perception of the importance of ADs in relation to different aspects, such as the need to prepare and make them available to the population, the approval of specific laws for ADs, classifying their importance as "very important", "not important" or "not at all important". After that, the participants evaluated the presented models, classifying them as "good", "acceptable" or "bad". They were also asked if they would recommend these models, in addition to evaluating their understanding and possible comprehension difficulties. Then, participants were invited to point out the important items of the AD, indicate a legal representative who was not present in the alternatives provided, and express the importance of health professionals talking to patients about AD. In total, 18 questions were presented, including closed and open questions. The two open questions regarded AD items that were not understood and the indication of a representative not mentioned in the alternatives.

The two AD models were model 1 (complete) and model 2 (abbreviated). These models were prepared by the authors after consulting international models, especially the one adopted by the County of Yukon, in Canada[20], and by the Autonomous Community of Catalonia, in Spain[21] due to its objective writing and easy-to-understand explanatory texts. In order to understand the answer difficulties, the models proposed for this study underwent several discussions in the Bioethics Committee of the University Hospital Santa Terezinha de Joaçaba, were submitted during the last years to several pre-tests in different cultural contexts, receiving the pertinent modifications.

AD Model 1. We present, below, an indicative model for the elaboration of a document on Advance Directives in which you can register your wishes to be fulfilled in a situation where you are unable to communicate, as well as designate a representative to participate in the decisions in your place. Carefully read the explanations for alternatives 1 and 2 and record your preferences. I ... CPF nº... RG nº... date of birth .../.../..., domiciled in ..., in the fullness of my mental faculties, freely and after prolonged reflection, declare: Part 1. Expression of wishes about health care. If I find myself in a situation where I cannot make decisions about my health care, my wishes regarding care and treatment are indicated in alternatives 1 or 2, which should serve as a guide for the professionals who assist me and my representative who will participate in the decision in my place. In both cases, comfort measures and palliative care are included when indicated.

1. Limited care. If, among the alternatives A-E, which are below, I mark "1. Limited care" means avoiding measures that do not benefit me. It only includes comfort measures, such as: nursing care, medication to minimize pain and suffering, oxygen, general care and emotional support. 2. Specific care. If, among the alternatives A-E, which are below, I mark "2. Specific care", in addition to comfort measures, I wish to receive other procedures that are indicated to me by the attending physician. I will express my wishes for five possible situations.

A. Terminal illness. If I find myself in the irreversible process of death, attested by two doctors, in which any life-sustaining treatment would only postpone it and prolong my suffering, I wish to receive: () 1. Limited care. () 2. Specific care. B. Permanent unconsciousness. If the disease is not terminal, but I am in a persistent coma, with no chance of regaining consciousness, attested by two doctors, I wish to receive: () 1. Limited care. () 2. Specific care. C. Brain injury. If the illness is not terminal, but there is demonstrably severe permanent brain damage that indicates an advanced stage of dementia, my wish is to receive: () 1. Limited care. () 2. Specific care. D. Kidney failure. If I find myself with a terminal illness (my death will occur in a few months) and my body has a permanent and serious failure of the functions of my vital organs that cannot be treated, such as the failure of both kidneys, with the need for permanent hemodialysis, I wish to receive: () 1. Limited care. () 2. Specific care. E. Respiratory failure. If I am terminally ill (my death will occur in a few months) and my body has a permanent and serious failure of the functions of my vital organs that cannot be recovered, such as severe respiratory failure, which requires continuous mechanical ventilation, I wish to receive: ( ) 1. Limited care. () 2. Specific care.

*Complete this item only if you checked alternative 2 in items A-E. When there is a medical indication, in addition to comfort measures and palliative care, I wish to receive some specific care that I will point out below: () Surgery. () Radiotherapy. () Intubation (in case of respiratory failure). () Renal dialysis (in case of failure of both kidneys). () Chemotherapy. () Blood transfusion. () Tube feeding. () Antibiotic therapy. () Other medications. () Other treatments. () Cardiopulmonary resuscitation. Explain if you want to clarify the choice: ...

Part 2. Manifestation of other wills: F. Regarding the donation of organs and tissues, my will is: () Not to donate. () Donate. () Donate only the following organs (describe which ones): ... G. Regarding Cremation: () Yes, I wish to be cremated. () I do not wish to be cremated. H. I have other wishes, for example: receiving spiritual/religious assistance, using experimental drugs, etc. (describe): ...

Part 3. Signature of witnesses and designation of representatives: Witnesses: 1. Name... CPF... Signature... 2. Name... CPF... Signature... I designate the representative (1) and his substitute (2) as people who can decide for me: 1) Name .... CPF ... Phone: ... Full address (include e-mail): ... 2) Name ... CPF... Phone: ... Full address (include e-mail): ... Date and Signature of declarant.

AD Model 2. We present, below, an abbreviated model for the elaboration of an Advance Directives document in which you can register your wishes to be fulfilled in a situation in which you are unable to communicate, as well as designate your representative to participate in the decisions in your place. Carefully read the explanations for alternatives 1 and 2 and record your preferences.

I... CPF nº.:. RG Nº. ..., date of birth.../.../..., domiciled on ..., in the fullness of my mental faculties, freely and after prolonged reflection, declare: Part 1. Manifestation of wills regarding health care. If I find myself unable to communicate, unable to make decisions, in very poor health that will cause me to die within months, or in a condition where there is little hope that I will regain a quality of life acceptable to me, my will with respect to the care and treatments I wish to receive is marked in alternatives 1 or 2, which should serve as a guide for the professionals who assist me and for my representative who will participate in the decision in my place. In both cases comfort measures and palliative care are included.

1. Limited care. If I check alternative 1, I want limited care and treatment. It means avoiding measures that do not benefit me, but it includes: nursing care, medication to minimize pain and suffering, oxygen, general care and emotional support. 2. Specific care. If I check alternative 2, I would like to receive some specific care and treatment. () 1. Limited care. Only comfort measures and palliative care. () 2. Specific care. It includes care other than comfort measures and palliative care.

If I have checked option 2, when there is a medical indication, I would like to receive care for the procedures or treatments that I will check below: () Surgery. ( ) Radiotherapy. ( ) Intubation. () Renal dialysis. () Chemotherapy. () Blood transfusion. () Tube feeding. () Antibiotic therapy. () Other medications. () Other treatments. () Cardiopulmonary resuscitation.

Part 2. Content identical to that presented in Part 2 of Model 1.

Part 3. Content identical to that presented in Part 3 of Model 1.

After the research, the models received the relevant modifications, which are available at: https://diretivasantecipadas.com.br/modeos-de-diretivas/[22]

Data were analyzed using bivariate statistics, using frequency tables. To define the number of classes for constructing the frequency table for the participants' age group, the Sturges equation was used. The chi-square test was used to verify the association between the variables sex, age group and education, and aspects related to AD, the result being considered significant when $p<0.05$.

RESULTS

Of the 163 participants who filled out the questionnaire, three of them were excluded from the study due to incomplete filling. It is observed (Fig. 1) that, of the 160 participants, the majority were female (69.37%) (Fig. 1a), aged between 60 and 69 years (55.65%) (Fig. 1b), and had only elementary education (51.88%) (Fig. 1c). As for profession, 55.7% were retired, 10.7% worked in agriculture and 7.5% were housewives. The remaining 26.1% were distributed among 26 different occupations.

As for knowledge, 85.62% had never heard of AD. Likewise, 98.13% of respondents did not know any model. There was no significant difference in terms of knowledge of ADs with regard to gender ($p=0.918$), age group ($p=0.915$) and education ($p=0.325$) of respondents.

Faced with each finding of lack of knowledge, an explanation of the AD was presented to the participants, taking the opportunity to resolve doubts regarding the document. Subsequently, the questionnaire on the perception of the importance of AD was followed (Table 1).

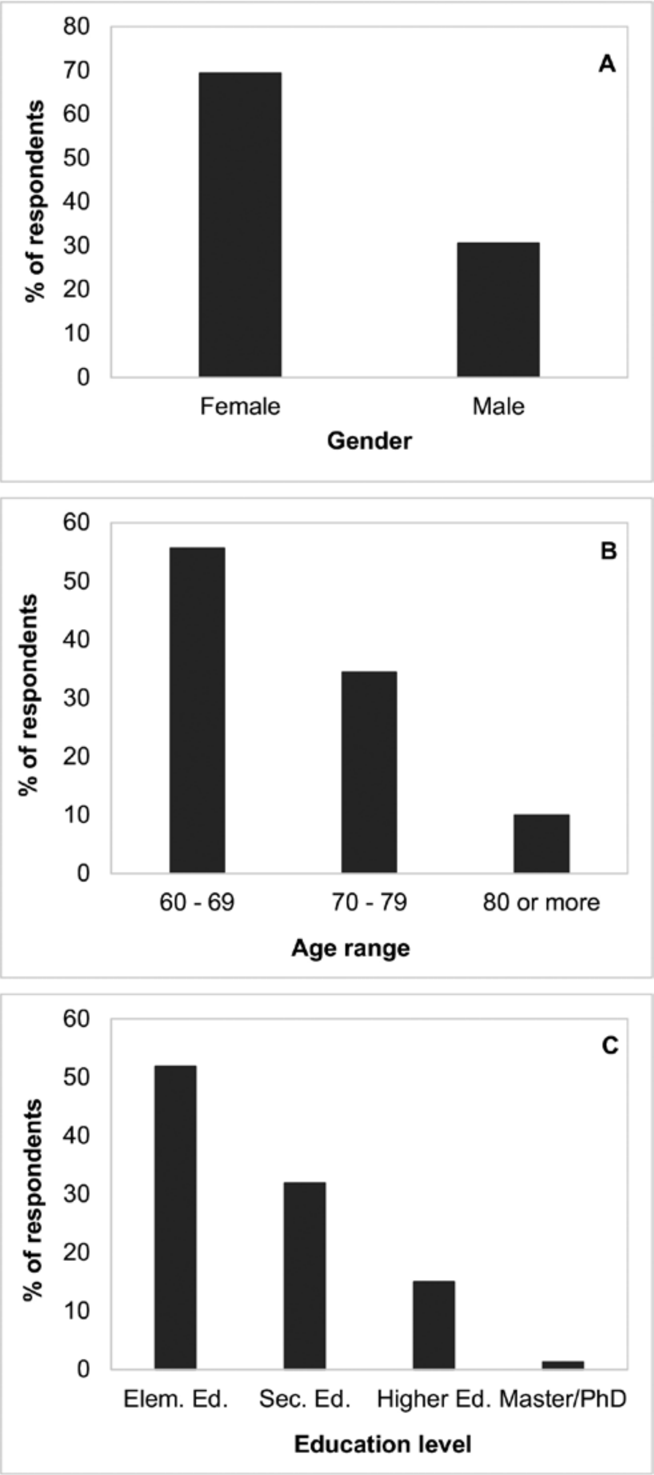

Figure 1. Profile of research participants regarding: a) gender (mas = male; fem = female); b) age range; c) education (Ens. Fund. = elementary education; Ens. médio = secondary education; Ens. sup. = higher education; Me = master's degree; Dr = doctorate). Joaçaba, SC, 2022.

Table 1. Perception of respondents regarding the importance of preparing, making available and passing a law on Advance Directives. Joaçaba, SC, 2022.

	Importance of preparing	Importance of making available	Importance of passing a law
	n (%)	n (%)	n (%)
Very important	147 (91.87)	146 (91.25)	146 (91.25)
Little important	11 (6.88)	12 (7.50)	11 (6.88)
Not important	2 (1.25)	2 (1.25)	3 (1.87)
Total	160 (100)	160 (100)	160 (100)

Comparing the perception of the importance of elaborating, making available and creating a specific law for AD between the groups separated by sex, age group and education, no significant differences were observed ($p>0.05$).

After explaining the ADs, the participants got to know and evaluated two models of ADs. From the results (Figure 2), it is observed that model 1 (complete) was better evaluated, receiving a classification of "good" by 72.50% of the respondents.

When asked to recommend one of the AD models, 63.75% of respondents recommended both models, 27.50% recommended model 1 and 8.75% recommended model 2. There was no significant difference in relation to the choice of model and gender ($p=0.969$), education ($p=0.814$) and age group ($p=0.962$) of respondents. However, it is important to highlight that 5% of the participants pointed out difficulties in understanding the models, especially with regard to the language of the questions (Table 2).

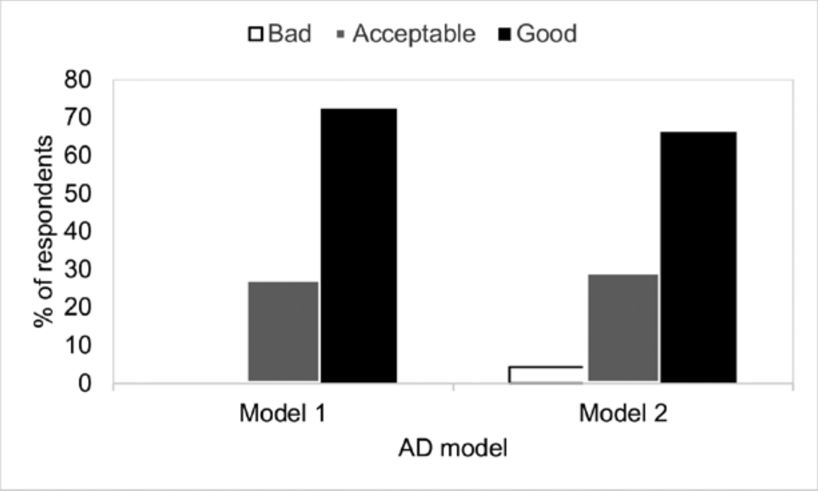

Figure 2. Evaluation, by the participants, of models 1 (complete) and 2 (abbreviated) of Advance Directives. Joaçaba, SC, 2022.

Table 2. Difficulty in understanding models of Advance Directives. Joaçaba, SC, 2022.

Specification of difficulties	n (%)
Language	4 (2.5)
Meaning of "treatment limitation".	1 (0.65)
Meaning of "health care" in model 2.	1 (0.65)
Did not specify	2 (1.2)

As for the importance of the AD items, 43.75% of the participants considered all the items important. The other participants indicated: designation of a legal representative (15%), organ donation (10%), limitation of treatments (8.75%), limitation of treatments and designation of a legal representative (8.13%), organ donation and limitation of treatments (5.63%), and designation of a legal representative and cremation (0.63%).

Given the emphasis on designating a legal representative, allowing for multiple responses, participants were asked who they would choose. The results were: adult child (66.88%), partner (11.25%), adult grandchild (1.88%), friend (0.63%), or any one of these options (19.37%).

Finally, participants were asked about the importance of health professionals talking to patients about preparing for the death process, as well as the importance of patients leaving guidelines through the AD. In this sense, 90% of respondents indicated that communication between health professionals and patients is important, while 88.75% considered it important to leave guidance about their wishes through the AD.

DISCUSSION

The older population is prone to reflection on the end of life, instigating the approach to the theme[23]. Regarding the knowledge of the participants about the AD, most were unaware of the device, a result similar to a survey carried out in a geriatrics outpatient clinic in Minas Gerais, with older patients and companions, in which only 3% knew the AD and 2% the CFM norm (Resolution 1995/12)[4].

However, the result was different from that reported in a survey carried out in Switzerland, applied to older people, where 78.7% had already heard about AD and 76.7% approved of them, especially women, showing the existing mismatch between countries[24]. In a study with cancer patients in the same region of the current research, most respondents were unaware of AD, but after clarifying their meaning, the desire to develop their own device was almost unanimous, evidencing the relevance of information for the implementation of AD in Brazil[25].

As for the difficulty in understanding the items presented in the research, the manifestations of will about limiting treatment and health care were pointed out. This finding emphasizes the need for prior clarifications, carried out by health professionals, for those who wish to complete the document. Decision-making about the future during the preparation of the ADs occurs in a context of solidary autonomy where the decision is shared[26]. Possible limitations in terms of education, beliefs or cultural differences require availability of time to explain the meaning of AD, clarifying doubts regarding treatment indications and restrictions, as well as contributing to the applicability of AD[27].

Often, low adherence to AD is associated with the country's culture and the lack of habit or resistance to talking about finitude[28]. In some countries, it is noted that the level of education is a factor that influences the knowledge of AD, as shown in a survey carried out in Switzerland[24].

It is estimated that the difficulties regarding the elaboration of ADs can be circumvented through carefully written documents, with advice and explanations about possibilities and treatment options[27]. Thus, directives are a promising way to exercise autonomy when there is no communication. When the participants of this research were questioned about the importance of elaborating ADs, the majority answered that they consider it important, with no difference by sex, education or age groups.

As for the participants' assessment of the AD models, there was better acceptance of model 1, although both were indicated by the majority. In this sense, the Brazilian Society of Geriatrics and Gerontology created the online application "Minhas Vontades" (My Will), accompanied by explanations that allow people to prepare their AD[29].

The passing of a law, which enables their right to autonomy, was evaluated as very important, by men and women, with no variation between age groups and education. In the Brazilian context, the initiative of the Ministry of Health should be highlighted, which included AD as guidelines for the organization of palliative care and cancer patients[7].

Thus, it is observed the existence of state legislation in Brazil that contributes to the execution of the right of patients to refuse painful or extraordinary medical treatments to prolong life[30]. Although they do not directly mention AD, among the various published laws, the most emblematic is the Covas Law (10,241/1999)[31].

In this scenario, the lack of progress is shown in a recent survey carried out at a teaching hospital in Curitiba-PR with physicians, nurses and nursing technicians and SUS users (patients and companions) in which most professionals (61.9%) and users (91.7%) were unaware of AD and the CFM Resolution 1995/2012[32].

Among the items that make up the AD models presented, all were considered important, but there was emphasis on the designation of the representative and organ donation. Regarding the representatives, the most mentioned were the adult children and the spouses. The appointment of a representative is accompanied by the need to keep them aware of your wishes. A Korean study elucidates that, among the reasons for registering their wishes in an AD, "not to burden families with end-of-life decisions" (82.1%), followed by "possibility of differences of opinion between themselves and other family members" (78.9%) and "due to the conscious risk of losing decision-making capacity in the event of an unexpected accident or serious illness” (75.9%)[33]. As for the order of choice of the representative, as in this research, in a study carried out in Malaysia, 38.8% of respondents chose their adult children and 22.4% their spouses, revealing that the preference is among the closest family members[34].

In this context, when it comes to the medical team, a survey carried out in a hospital in RS pointed out that physicians have difficulty in following the desire expressed by the patient in AD when the family is against it, demonstrating the need for greater prior communication between the team, patient and family members, otherwise new dilemmas may arise[27].

With regard to the importance of preparing ADs and making them available to the population, it is inferred that the lack of federal legislation and lack of knowledge about ADs contribute to the non-appearance of significant differences in understanding. A survey showed that both professionals and users of health services point to the need for the physician to take the initiative to talk about ADs[32]. A promising aspect was that 95% of Brazilian medical students interviewed in a survey attributed this function to the physician, demonstrating that they were already aware of the topic[35].

In the present research, the participants considered it important that health professionals take the initiative to talk about death and that patients leave their wishes in writing. However, the results of one study attribute the low adherence of physicians to AD to lack of knowledge and experience, paternalism, difficulties in defining the patient's prognosis, legal concerns, the influence of family members, in addition to cultural and religious factors[36]. However, it is necessary for health professionals to have acquired skills on AD in order to guide their patients, in addition to striving to ensure that their wishes are fulfilled[37]. On the other hand, conditions must be created, especially from a legal point of view, so that patients have the means to make their directives available.

This research has as limitations the regional character and the number of its sample, making generalizations difficult. Furthermore, the population's lack of knowledge about AD may have caused a bias in the acceptance and evaluation of the presented models, as well as in explaining the lack of difference in responses between the groups.

CONCLUSION

The results allow us to conclude that the evaluated older population knew little about Advance Directives. However, after knowing its purpose, they considered its elaboration important, preferred the more complete model and, as a legal representative, the adult children and spouses.

Almost all considered it necessary to pass a law to encourage the implementation of Advance Directives in Brazil and guarantee the accessibility of this right to the population. It is understood that, for the benefits to become real, legal, cultural and structural changes are necessary in health institutions, professional entities and educational institutions. Finally, there is a need to prepare health professionals, starting from graduation, in the discipline of Bioethics or through specific courses, to approach this right that is so important to the population.

AUTHORSHIP

- Gustavo S. Vanzella - conception and design of the study, analysis and interpretation of data, data collection, writing of the manuscript.
- Isadora C. D. Souza - conception and design of the study, analysis and interpretation of data, data collection, writing of the manuscript.
- Juliano C. Ferreira - data collection and writing of the manuscript.
- Vilma Beltrame - conception and design of the study, analysis and interpretation of data and writing of the manuscript.
- Sirlei Favero Cetolin - conception and design of the study, analysis and interpretation of data and writing of the manuscript.
- Elcio L. Bonamigo - conception and design of the study, analysis and interpretation of data, writing of the manuscript, critical revision of the text and general responsible for the study. All authors approved the final version of the manuscript.

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