

# Advance directives: autonomy tool for cancer patients

Christiane Veigas Pepes<sup>1</sup>, Mariane Veigas Pepes<sup>1</sup>, Janaína Neuhauser<sup>1</sup>, José Carlos Abellán Salort<sup>2</sup>, Jovani Antônio Steffani<sup>1</sup>, Elcio Luiz Bonamigo<sup>1</sup>

1. Universidade do Oeste de Santa Catarina, Joaçaba/SC, Brasil. 2. Universidad Rey Juan Carlos, Madrid, España.

## Abstract

Advance directives allow patients to assign a legal representative and express their wishes to be fulfilled when they can no longer communicate. This study evaluated cancer patients' knowledge and preferences regarding these directives. A cross-sectional quantitative research was conducted by filling out two advance directive models and a questionnaire. Of the total sample, 87.38% had never heard of such document, 97.2% ignored the two models available and 95% had no difficulties filling it out. After clarifications, 93.46% considered it important for all patients to write a directive, 94.86% expressed that advance directives should be made available to patients and 91.12% argued that a federal law should be passed. Explaining the concept of advanced directives increased the interest of cancer patients in exercising this right which strengthen their autonomy.

**Keywords:** Advance directive adherence. Palliative care. Medical oncology. Personal autonomy. Patient rights. Advance directives.

## Resumo

### Diretivas antecipadas de vontade: instrumento de autonomia para pacientes oncológicos

Diretivas antecipadas de vontade permitem que pacientes designem um representante legal e manifestem seus desejos a serem cumpridos quando se tornarem incapazes de se comunicar. Neste estudo, objetivou-se avaliar o conhecimento e as preferências de pacientes oncológicos sobre essas diretivas. Trata-se de pesquisa quantitativa e transversal realizada por meio do preenchimento de dois modelos de diretivas antecipadas de vontade e da aplicação de um questionário. Constatou-se que 87,38% dos pacientes nunca tinham ouvido falar em tais diretivas, 97,2% desconheciam os modelos e 95% não referiram dificuldade de preenchimento. Após o esclarecimento, 93,46% consideraram importante que todas as pessoas elaborem as diretivas, 94,86% que elas sejam disponibilizadas aos pacientes e 91,12% que seja aprovada uma lei federal. O esclarecimento sobre o conceito de diretivas antecipadas de vontade contribuiu para aumentar o interesse de pacientes oncológicos pela utilização desse direito, que fortalece sua autonomia pessoal quando incapazes de se comunicar.

**Palavras-chave:** Adesão a diretivas antecipadas. Cuidados paliativos. Oncologia. Autonomia pessoal. Direitos do paciente. Diretivas antecipadas.

## Resumen

### Directivas anticipadas: un instrumento de autonomía para los pacientes oncológicos

Las directivas anticipadas permiten a los pacientes designar a un representante legal y manifestar sus decisiones cuando no puedan comunicarse. Este estudio evaluó el conocimiento y las preferencias de los pacientes oncológicos sobre este documento. Se realizó una investigación cuantitativa y transversal, mediante la respuesta a dos modelos de directivas anticipadas y la aplicación de un cuestionario. El 87,38% de los pacientes no conocían este documento, el 97,2% de ellos desconocían los modelos y el 95% declararon no tener dificultades para responderlos. Tras la aclaración, el 93,46% de los entrevistados consideraban importante que todos elaboraran el documento, el 94,86% que debían ponerlo a disposición de los pacientes y el 91,12% que se aprobara una ley federal. La aclaración del concepto de voluntades anticipadas contribuye a incrementar el interés de los pacientes oncológicos por hacer uso de este derecho, que refuerza su autonomía personal cuando ya no pueden comunicarse.

**Palabras clave:** Adhesión a las directivas anticipadas. Cuidados paliativos. Oncología. Autonomía personal. Derechos del paciente. Directivas anticipadas.

The authors declare no conflict of interest.

Approval CEP-Unoesc 4868841

Advance directives (ADs) are defined in Art. 1 of Resolution 1,995/2012 by the Federal Council of Medicine as a *set of explicit wishes made in advance by a patient regarding the care and treatments they wish to receive or avoid if they are rendered unable to express their will freely and autonomously*<sup>1</sup>.

These directives consist of two components: the living will and the appointment of a representative, also known as a durable power of attorney. The living will outlines the medical care preferences of the patient when they cannot communicate, while the appointed representative is entrusted, either temporarily or permanently, to make decisions on behalf of the patient<sup>2</sup>.

Emerging amidst an aging population, shifts in the epidemiological landscape toward chronic degenerative diseases, and significant scientific advancements, ADs serve as crucial tools in preserving human autonomy<sup>3</sup>. However, for clinical decisions to reflect a patient's ADs, the will should undergo periodic reviews, given the constant evolution of medicine in parallel with scientific advancements, necessitating a dynamic document<sup>4</sup>.

The concept of the living will emerged in 1969, introduced by American lawyer Luis Kutner under the name *living will*, enabling individuals to refuse futile medical treatments aimed solely at prolonging life<sup>5</sup>. In 1991, the United States enacted the Patient Self-Determination Act, the inaugural federal law granting individuals the right to complete their ADs, as highlighted by Cogo and Lunardi<sup>6</sup>.

Within the European Union, 15 out of 28 countries have specific legislation regulating ADs<sup>7</sup>, with Spain pioneering their legalization through Law 41/2002<sup>8</sup> under the name *instrucciones previas* and contextualizing them within the framework of patient autonomy<sup>9</sup>. In 2012, Portugal implemented legislation regulating ADs and established the National Registry on Living Wills (Rentev), enabling the designation of a healthcare proxy<sup>10</sup>. More recently, in 2017, Italy introduced its law, labeling the directives as *disposizioni advance di trattamento*<sup>11</sup>.

Across Latin America, Puerto Rico led the way in 2001 with legislation on Advance Directives for Treatment (Law 160), followed by Mexico in 2008 (*Ley de Voluntad Anticipada*), Argentina (Federal Law 26,742), and Uruguay (Law 18,473)—all from 2009—then Colombia enacted Law 1,733 in 2014<sup>12</sup>. In Brazil, Resolution CFM 1,995/2012<sup>1</sup> was the pioneering standard aiming to regulate the preparation of ADs. Despite the current absence of federal legislation, Bill 149/2018<sup>13</sup> is undergoing processing in the Federal Senate, with a public hearing scheduled for further discussion.

As it brings forth a broad and negative symbolic spectrum, the news of a cancer diagnosis holds various meanings impacting a patient's future, involving seldom-discussed topics in everyday life such as invasive treatments and the finite nature of life<sup>14</sup>. The potential loss of communication ability underscores the importance of ADs as an effective means to uphold a patient's autonomy and dignity<sup>3</sup>.

Among cancer patients in Toronto, Canada, the majority (53%) had formulated their ADs before being diagnosed with cancer<sup>15</sup>. Likewise, research conducted in Germany among patients with head and neck cancer revealed that nearly half (46.4%) had prepared such directives<sup>16</sup>.

However, it is crucial to consider that the creation of these directives hinges on awareness about them. After being informed about the significance of ADs, the majority of cancer patients and caregivers who were previously unaware expressed the intent to prepare them<sup>17</sup>. Similarly, research among cancer patients in the same region revealed a parallel trend: nearly all were unaware of ADs, but upon understanding their significance, they expressed a keen interest in drafting them, with the majority showing intent to do so<sup>18</sup>. This underscores the pivotal role of awareness and comprehension of this tool for individuals to consider its adoption.

It is consequently evident that a considerable number of cancer patients lack awareness of ADs. Likewise, there is a high likelihood of a substantial cohort of such patients expressing interest in formulating these directives, justifying the pursuit of this research. Hence, the primary aim of this article was to assess the knowledge, preferences, and perceptions of cancer patients regarding ADs and to gauge their acceptance of AD implementation in Brazil.

## Method

This study is a cross-sectional and descriptive research, employing a quantitative approach, conducted among cancer patients at the Hospital Universitário Santa Terezinha (Hust) in the western region of Santa Catarina, spanning from March through May 2022. A total of 214 participants were selected, considering the overall population of cancer patients listed in the hospital registry, with a margin of error of 5% and a 95% reliability index.

Convenience sampling was utilized, approaching research participants in the oncology consultation ward or hospitalization area. Inclusion criteria involved individuals over 18 years old who consented to the informed consent form, while those experiencing any form of disorientation were excluded.

Data collection was conducted by three pre-instructed medical students, explaining the project's nature to participants and ensuring confidentiality and privacy, emphasizing participants' rights to withdraw from the research at any stage. Initially, the objectives of ADs were clarified to patients after acceptance, followed by the application of two models of this document, with or without interviewer assistance as required. Upon completion, a 28-question survey was administered.

Responses were quantified in terms of absolute and relative frequencies, with qualitative variables counted and compared using the chi-square association test concerning gender, education, age group, and duration since diagnosis. Data analysis was performed using the Statsmodels statistical package in the Python 3.9 programming language.

## Results

The sample comprised 214 participants who completed the survey: 132 were female (61.7%) and 82 were male (38.3%). Their mean age was  $52.7 \pm 14.2$ , ranging from 19 to 86 years old.

In terms of education, 85 had finished primary schooling (39.7%), 90 had completed secondary education (42.1%), 34 had attained higher education (15.9%), and five held a master's/doctorate (2.3%).

Various cancer types were reported, with breast cancer being the most prevalent ( $n=69$ , 29.44%), followed by intestinal cancer ( $n=39$ , 18.22%), lung cancer ( $n=15$ , 7%), stomach cancer ( $n=10$ , 4.67%), and prostate cancer ( $n=9$ , 4.2%). The mean time since diagnosis was  $23.25 \pm 30.44$  months.

Most participants (187; 87.38%) were unfamiliar with ADs, and nearly all (208; 97.20%) were unaware of available elaboration models. However, upon learning about the researched document, the majority (170; 79.44%) found it important to discuss treatment limitations. Additionally, 71.96% (154) expressed support for the option to donate their bodies, and 71.03% (152) favored the ability to appoint a representative.

Nearly all (200; 93.46%) considered it crucial for individuals to prepare their ADs, and 94.86% (203) believed it was important for health departments to provide model directives to patients. A vast majority (195; 91.12%) viewed it as important for the National Congress to pass legislation on ADs. Subsequently, the responses will be presented based on age group, education level, and time since diagnosis.

### Results by age group

Participants were split into three subgroups according to age group: 18-30 years old ( $n=13$ ), 31-60 years old ( $n=125$ ), and over 60 years old ( $n=76$ ). The results are shown in Table 1.

When comparing the age groups, participants aged 18-30 years exhibited significantly greater awareness regarding the existence of ADs elaboration models ( $p=0.0001$ ) (Table 1). Other data did not demonstrate a significant difference ( $p>0.05$ ). Nevertheless, although not statistically significant, as age increased, the number of participants who deemed it crucial for individuals to prepare their ADs increased.

**Table 1.** Responses by the total number of participants and split by age group.

| Questions related to ADs                               | Answers    | Total % (n)<br>100 (214) | 18-30 % (n)<br>6.07 (13) | 31-60 % (n)<br>58.41 (125) | <+60 % (n)<br>35.51 (76) | <i>p</i> |
|--|------------|--------------------------|--------------------------|----------------------------|--------------------------|----------|
| Have you heard of ADs?                                 | Yes        | 12.62 (27)               | 23.08 (3)                | 12.0 (15)                  | 11.84 (9)                | 0.5029   |
|  | No         | 87.38 (187)              | 76.92 (10)               | 88.0 (110)                 | 88.16 (67)               |          |
| Did you know the AD model?                             | Yes        | 2.80 (6)                 | 23.08 (3)                | 1.6 (2)                    | 1.32 (1)                 | 0.0001   |
|  | No         | 97.20 (208)              | 76.92 (10)               | 98.4 (123)                 | 98.68 (75)               |          |
| Is it relevant to choose treatment limitations?        | Yes        | 79.44 (170)              | 69.23 (9)                | 80.8 (101)                 | 78.95 (60)               | 0.6119   |
|  | No         | 20.56 (44)               | 30.77 (4)                | 19.2 (24)                  | 21.05 (16)               |          |
| Is it relevant to designate a representative?          | Yes        | 71.03 (152)              | 69.23 (9)                | 68.0 (85)                  | 76.32 (58)               | 0.4471   |
|  | No         | 28.97 (62)               | 30.77 (4)                | 32.0 (40)                  | 23.68 (18)               |          |
| Organ donation: is it relevant to express your desire? | Yes        | 71.96 (154)              | 61.54 (8)                | 73.6 (92)                  | 71.05 (54)               | 0.6385   |
|  | No         | 28.04 (60)               | 38.46 (5)                | 26.4 (33)                  | 28.95 (22)               |          |
| Is it relevant to work on ADs?                         | Very much  | 93.46 (200)              | 84.62 (11)               | 92.8 (116)                 | 96.05 (73)               | 0.2742   |
|  | Not much   | 6.54 (14)                | 15.38 (2)                | 7.2 (9)                    | 3.95 (3)                 |          |
| The health department needs to make ADs available?     | Very much  | 94.86 (203)              | 84.62 (11)               | 96.8 (121)                 | 93.42 (71)               | 0.0910   |
|  | Not much   | 4.21 (9)                 | 15.38 (2)                | 3.2 (4)                    | 3.95 (3)                 |          |
|  | Not at all | 0.93 (2)                 | 0 (0)                    | 0 (0)                      | 2.63 (2)                 |          |
| Is it important to pass a law on ADs?                  | Very much  | 91.12 (195)              | 84.62 (11)               | 90.4 (113)                 | 93.42 (71)               | 0.3423   |
|  | Not much   | 6.07 (13)                | 15.38 (2)                | 7.2 (9)                    | 2.63 (2)                 |          |
|  | Not at all | 2.80 (6)                 | 0 (0)                    | 2.4 (3)                    | 3.95 (3)                 |          |

ADs: advance directives

### Results by educational background

Regarding frequencies based on education, participants were categorized into four groups: elementary education (n=85), secondary education (n=90), complete higher education (n=34), and master's/doctorate (n=5), detailed in Table 2.

Individuals in the master's/doctorate group indicated a stronger inclination towards designating a representative, with a statistically significant result ( $p=0.0340$ ). However, they considered it less important to speak out about the limitation of procedures, and this result was very close to being

significant ( $p=0.0751$ ). No other responses yielded statistically significant differences ( $p>0.05$ ) (Table 2).

Participants across all educational categories initially displayed limited or no prior familiarity with ADs. However, upon becoming acquainted with them—especially among those with higher education—they have almost unanimously regarded it as crucial for individuals to present their ADs. There was also a widespread consensus on the significance of making these directives accessible to the public and regulating them through the enactment of a national law (Figure 1).

**Table 2.** Responses regarding participants' educational background

| Questions related to ADs | Answers | Elementary school % (n)<br>39.72 (85) | High school % (n)<br>42.06 (90) | University education % (n)<br>15.89 (34) | Master's/PhD % (n)<br>2.34 (5) | <i>p</i> |
|--------------------------|---------|---------------------------------------|---------------------------------|--|--------------------------------|----------|
| Have you heard of ADs?   | Yes     | 9.41 (8)                              | 16.67 (15)                      | 11.76 (4)                                | 0 (0)                          | 0.4113   |
|                          | No      | 90.59 (77)                            | 83.33 (75)                      | 88.24 (30)                               | 100.0 (5)                      |          |

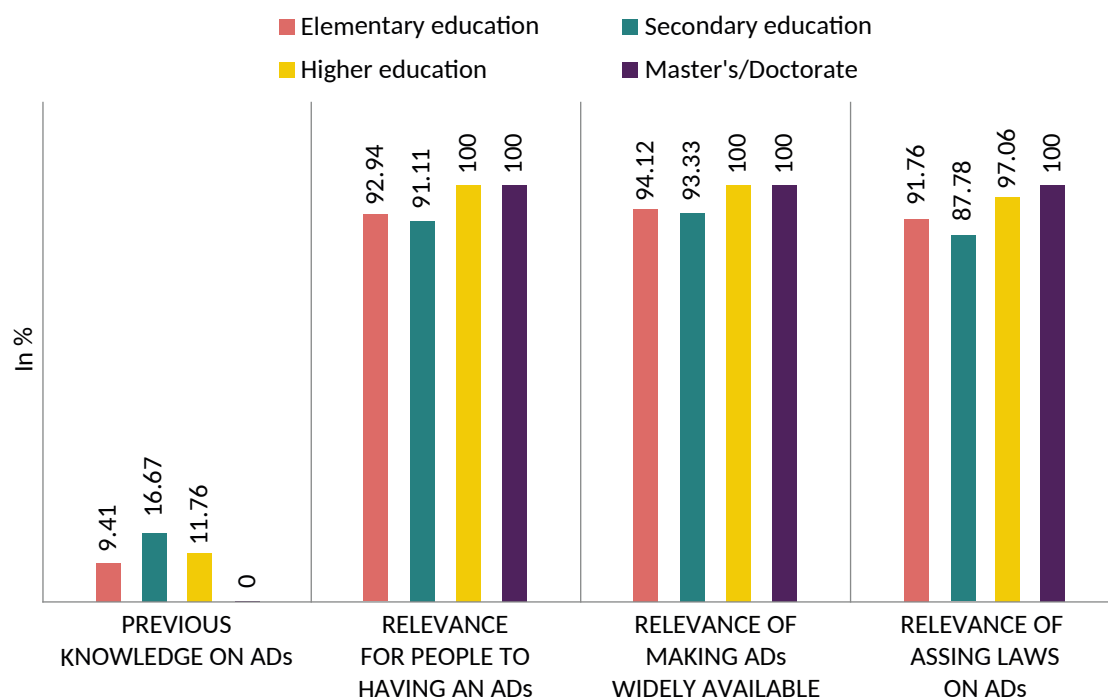
continues...

**Table 2.** Continuation

| Questions related to ADs                               | Answers    | Elementary school % (n)<br>39.72 (85) | High school % (n)<br>42.06 (90) | University education % (n)<br>15.89 (34) | Master's/ PhD % (n)<br>2.34 (5) | p      |
|--|------------|---------------------------------------|---------------------------------|--|---------------------------------|--------|
| Did you know the AD model?                             | Yes        | 0 (0)                                 | 5.56 (5)                        | 2.94 (1)                                 | 0 (0)                           | 0.1647 |
|  | No         | 100.0 (85)                            | 94.44 (85)                      | 97.06 (33)                               | 100.0 (5)                       |        |
| Is it relevant to choose treatment limitations?        | Yes        | 85.88 (73)                            | 72.22 (65)                      | 85.29 (29)                               | 60.0 (3)                        | 0.0751 |
|  | No         | 14.12 (12)                            | 27.78 (25)                      | 14.71 (5)                                | 40.0 (2)                        |        |
| Is it relevant to designate a representative?          | Yes        | 76.47 (65)                            | 71.11 (64)                      | 52.94 (18)                               | 100.0 (5)                       | 0.0340 |
|  | No         | 23.53 (20)                            | 28.89 (26)                      | 47.06 (16)                               | 0 (0)                           |        |
| Organ donation: is it relevant to express your desire? | Yes        | 69.41 (59)                            | 70.0 (63)                       | 79.41 (27)                               | 100.0 (5)                       | 0.3436 |
|  | No         | 30.59 (26)                            | 30.0 (27)                       | 20.59 (7)                                | 0 (0)                           |        |
| Is it relevant to work on ADs?                         | Very much  | 92.94 (79)                            | 91.11 (82)                      | 100.0 (34)                               | 100.0 (5)                       | 0.3108 |
|  | Not much   | 7.06 (6)                              | 8.89 (8)                        | 0 (0)                                    | 0 (0)                           |        |
| The health department needs to make ADs available?     | Very much  | 94.12 (80)                            | 93.33 (84)                      | 100.0 (34)                               | 100.0 (5)                       | 0.8497 |
|  | Not much   | 4.71 (4)                              | 5.56 (5)                        | 0 (0)                                    | 0 (0)                           |        |
|  | Not at all | 1.18 (1)                              | 1.11 (1)                        | 0 (0)                                    | 0 (0)                           |        |
| Is it important to pass a law on ADs?                  | Very much  | 91.76 (78)                            | 87.78 (79)                      | 97.06 (33)                               | 100.0 (5)                       | 0.6874 |
|  | Not much   | 4.71 (4)                              | 8.89 (8)                        | 2.94 (1)                                 | 0 (0)                           |        |
|  | Not at all | 3.53 (3)                              | 3.33 (3)                        | 0 (0)                                    | 0 (0)                           |        |

ADs: advance directives

**Figure 1.** Responses on knowledge and the significance of advance directives based on participants' educational background.



Research

## Results by time since diagnosis

For the analysis of frequencies concerning the time since diagnosis, participants were split into four distinct groups: 0-12 months (n=128), 13-24 months (n=34), 25-36 months (n=14), and over 36 months (n=38). There was a notable difference in responses concerning awareness of models for developing ADs based on the time of illness. Participants diagnosed between 0-12 months or over 36 months tended to provide more negative responses, with statistically significant discrepancy ( $p=0.0029$ ). Other findings did not demonstrate statistical significance ( $p>0.05$ ).

Out of the 214 participants surveyed, 12 individuals (5.6%) reported difficulty understanding certain aspects of the presented documents, while 143 (94.4%) indicated a solid understanding. The difficulties highlighted included language barriers mentioned by seven participants (3.1%), ambiguity in understanding the term “other wishes” by two individuals (1%), and difficulties understanding “limitation of treatments,” “other treatments,” and “healthcare” by one participant each (0.5%).

## Discussion

The prevalence of breast cancer significantly contributed to the higher representation of women among the participants. Globally, in 2018, breast cancer was the most prevalent (11.7%), followed by lung cancer (11.4%), colorectal cancer (10%), prostate cancer (7.3%), and stomach cancer (5.6%)<sup>19</sup>. Despite therapeutic advancements, cancer remains a serious concern, with an expected 60% increase in global cancer incidence by 2040<sup>20</sup>.

Upon receiving a cancer diagnosis, individuals often grapple with uncertainty regarding a cure and become more open to contemplating end-of-life issues<sup>21</sup>. When queried about their awareness of ADs, most participants (87.38%) reported no prior knowledge about them (Table 1). Notably, the Brazilian Ministry of Health included ADs in palliative care guidelines for cancer patients in 2018<sup>22</sup>. Equivalent results were found in two Brazilian studies conducted with oncology patients, demonstrating almost complete unawareness among participants in the assessment using the Likert scale<sup>3,18</sup>.

In this research, despite the prior lack of awareness observed across all educational groups, after being informed of its purpose, nearly all interviewees (93.46%) considered the development of an AD to be highly important (Table 1, Figure 1). A survey conducted with 148 lung cancer patients in western China showed that 94.6% (140) were initially unaware of the directives, but after understanding their concept, 79.7% (118) expressed willingness to fill in a template to document their preferences<sup>17</sup>. Similarly, in a related study in the same region, after clarifying the meaning of ADs, the majority (62%) of cancer patients expressed a desire to prepare them, highlighting a recent surge in regional acceptance due to increased awareness<sup>18</sup>.

In a study involving patients with advanced cancer, half of the participants identified the lack of information as a substantial obstacle to completing their ADs<sup>15</sup>. Hence, inadequate knowledge stands as a key determinant for low adherence, emphasizing that clarification plays a pivotal role in achieving nearly unanimous acceptance. A survey in Spain in 2012 found that most healthcare users (86.2%) were unaware of ADs<sup>8,23</sup>. However, a 2020 study in two hospital internal medicine services reported that 80.36% of participants were knowledgeable about ADs, coinciding with the recent increase in information dissemination to the population<sup>24</sup>.

Education, beliefs, and cultural backgrounds can significantly influence the practicality of ADs<sup>3</sup>. Evidence suggests that a higher level of education positively correlates with greater adherence to ADs, as evidenced by a survey involving 526 cancer patients in China<sup>25</sup>. Individuals with a heightened awareness of their rights tend to value the opportunity to assert their autonomy through these documents, which was particularly observed among those with higher education levels, including those with higher education and master's or doctorate degrees (Figure 1).

An intriguing discovery in this study was the increasing emphasis placed on the preparation of ADs in tandem with advancing age groups. Nearly all older adult patients (96.05%) deemed it “very important” for everyone to prepare their ADs. In Spain, age disparities were evident in AD registration, which was more frequent among those aged over 60<sup>26</sup>.

The significance attributed to ADs varies among European countries<sup>27</sup>. In Germany, a study highlighted a higher preparation rate among older individuals, those in marital or stable relationships, and those adhering to regular medication regimens<sup>15</sup>.

The appointment of a legal representative emerged as a significant aspect, particularly among older adults with prolonged diagnoses and those with a master's or doctorate (Table 1). A study carried out with 346 patients from a Brazilian oncology reference hospital found that nearly all participants deemed it crucial to designate a representative for decision-making<sup>3</sup>. Given that not every circumstance can be anticipated in the AD, appointing a representative familiar with the patient's wishes aids in respecting their autonomy.

Most participants in this study regarded incorporating their preferences into ADs as important (Table 1). This device contributes to diminishing futile care and invasive treatments intended solely to extend a poor quality of life. A retrospective study of 422 deceased patients post-bone marrow transplantation revealed that those who completed their ADs and declined futile treatments had a higher chance of avoiding such interventions<sup>28</sup>.

Regarding expressing a desire to donate organs through ADs, while not everyone may be eligible, the majority of participants agreed on registration and donation (Table 1), with 100% agreement among those with a master's or doctorate (Table 2). Higher education levels appear to correlate with a heightened willingness to donate organs. This trend is reflected among 30 medical professionals from a university hospital, all of whom agreed to organ donation, surpassing those with lower educational qualifications<sup>29</sup>.

Up until the time of this study, Brazil lacked federal legislation concerning ADs. However, upon becoming aware of its existence, the majority of participants viewed it as essential to establish a national law and ensure its availability through municipal health departments, aiming to guarantee access for the entire population (Table 1). A similar sentiment was evident in another study within the same region, where 90.9% of cancer patients undergoing treatment

and 94.4% of their companions advocated for the approval of national legislation on ADs in Brazil<sup>18</sup>.

This significance was also underscored in a German study involving 503 oncology and hematology patients, with the majority (54%) initiating their AD preparations only after the law came into effect. However, they expressed a need for more information from their healthcare providers<sup>30</sup>. Beyond the establishment of laws related to ADs, the critical importance of disseminating information among patients and healthcare professionals emerges as a pivotal factor in increasing adherence and, consequently, promoting autonomy. Among healthcare professionals, the necessity for knowledge among doctors and nursing staff emerges as a crucial factor for effective AD implementation<sup>31</sup>.

Formal models for filling out ADs are lacking in Brazil<sup>32</sup>. Nonetheless, a minority of patients, approximately 5%, encountered difficulties understanding the templates presented by the authors, an issue primarily related to the language used. Since it might be challenging to further simplify the models under development, it is estimated that guidance from a healthcare professional during completion would adequately address such questions without compromising the information.

## Final considerations

The study revealed that cancer patients initially lacked awareness about ADs, yet after receiving clarification about its purpose and components, almost all participants accepted and embraced the concept. Similarly, there was nearly unanimous approval and acknowledgment of the importance of making ADs models available for those interested in completing them, alongside the need for a national law to regulate them.

It can be concluded that providing clarity on ADs significantly boosts people's inclination to prepare them, emphasizing the need for a national law to ensure access to this right for the population.

This research had limitations, primarily focusing on a single category of patients. Moreover, researchers encountered the challenge of patients

lacking knowledge about directives and their objectives, highlighting the necessity for broader public dissemination of this information. On the other hand, the low level of difficulty pointed out by participants encourages the use of the AD models currently under development.

Ultimately, these findings serve as a springboard for further research on this tool, encouraging expanded access to its development. Such advancements aim to empower patient autonomy, particularly in situations where communication might be impaired.

*This research was funded by the Fundação de Amparo à Pesquisa e Inovação de Santa Catarina (Public call 12/2020; Grant term: TR2021000583; Universal Research Program).*

## References


1. Conselho Federal de Medicina. Resolução nº 1.995, de 9 de agosto de 2012. Dispõe sobre as diretivas antecipadas de vontade dos pacientes. Diário Oficial da União [Internet]. Brasília, p. 269-70, 31 ago 2012 [acesso 18 set 2023]. Seção 1. Disponível: <https://bit.ly/497SGtW>
2. Dadalto L. Reflexos jurídicos da resolução CFM 1.995/12. Rev. bioét. (Impr.) [Internet]. 2013 [acesso 18 set 2023];21(1):106-12. Disponível: <https://bit.ly/46KCXPR>
3. Santana SCG, Câmara DB. Percepção e expectativas de pacientes com câncer acerca das diretivas antecipadas de vontade. Rev Bras Cancerol [Internet]. 2022 [acesso 18 set 2023];68(1):e-181625. DOI: 10.32635/2176-9745.RBC.2022v68n1.1625
4. Dadalto L, Tupinambás U, Greco DB. Diretivas antecipadas de vontade: um modelo brasileiro. Rev. bioét. (Impr.) [Internet]. 2013 [acesso 18 set 2023];21(3):463-76. Disponível: <https://bit.ly/46Hru3v>
5. Lazarin GV. Diretivas antecipadas de vontade: análise constitucional do direito fundamental à morte digna. Revista Eletrônica Ajufesc [Internet]. 2019 [acesso 18 set 2023];9(1):1-24. Disponível: <https://bit.ly/46HrikN>
6. Cogo SB, Lunardi VL. Diretivas antecipadas: uma análise documental no contexto mundial. Texto Contexto Enferm [Internet]. 2018 [acesso 18 set 2023];27(3):1-9. DOI: 10.1590/0104-070720180001880014
7. Rodado EP, Sanchez DP, Grifo MG. Advance directives: comparison of current legislation within the European Union. Spanish J Legal Med [Internet]. 2021 [acesso 18 set 2023];47(2):66-73. DOI: 10.1016/j.remle.2020.05.011
8. España. Ley nº 41, de 14 de noviembre de 2002. Básica reguladora de la autonomía del paciente y de derechos y obligaciones en materia de información y documentación clínica. Boletín Oficial del Estado [Internet]. Madrid, nº 274, p. 40126, 15 nov 2002 [acesso 18 set 2023]. Disponível: <https://bit.ly/46B1ozf>
9. Salort JCA, Lanzarot AB. Autonomía, libertad y testamento vital: régimen jurídico y publicidad. Madrid: Dykinson; 2009.
10. Portugal. Lei nº 25, de 16 de julho de 2012. Regula as diretivas antecipadas de vontade, especialmente sob a forma de testamento vital, e a nomeação de procurador de cuidados de saúde e cria o Registo Nacional do Testamento Vital (RENTEV). Diário da República [Internet]. Lisboa, nº 136, p. 3728-30, 16 jul 2012 [acesso 18 set 2023]. Série 1. Disponível: <https://bit.ly/477cQCH>
11. Italia. Legge 22 dicembre 2017, nº 219. Norme in materia di consenso informato e di disposizioni anticipate di trattamento. Gazzetta Ufficiale [Internet]. Roma, nº 12, 16 jan 2018 [acesso 18 set 2023]. Disponível: <https://bit.ly/3QvWvSs>
12. Monteiro RSF, Silva AG Jr. Diretivas antecipadas de vontade: percurso histórico na América Latina. Rev. bioét. (Impr.) [Internet]. 2019 [acesso 18 set 2023];27(1):86-97. DOI: 10.1590/1983-80422019271290
13. Brasil. Senado federal. Projeto de Lei do Senado nº 149, de 2018. Dispõe sobre as diretivas antecipadas de vontade sobre tratamentos de saúde. Senado Federal [Internet]. 4 abr 2018. [acesso 18 set 2023]. Disponível: <https://bit.ly/3FsBYYN>
14. Geovanini F, Braz M. Conflitos éticos na comunicação de más notícias em oncologia. Rev. bioét. (Impr.) [Internet]. 2013 [acesso 18 set 2023];21(3):455-62. Disponível: <https://bit.ly/3Mcfm2r>



15. McDonald JC, du Manoir JM, Kevork N, Le LW, Zimmermann C. Advance directives in patients with advanced cancer receiving active treatment: attitudes, prevalence, and barriers. *Support Care Cancer* [Internet]. 2017 [acesso 18 set 2023];25(2):523-31. DOI: 10.1007/s00520-016-3433-6
16. Allner M, Gostian M, Balk M, Rupp R, Allner C, Mantsopoulos K *et al.* Advance directives in patients with head and neck cancer: status quo and factors influencing their creation. *BMC Palliat Care* [Internet]. 2022 [acesso 18 set 2023];21(1):47. DOI: 10.1186/s12904-022-00932-5
17. Feng C, Wu J, Li J, Deng HY, Liu J, Zhao S. Advance directives of lung cancer patients and caregivers in China: a cross sectional survey. *Thorac Cancer* [Internet]. 2020 [acesso 18 set 2023];11(2):253-63. DOI: 10.1111/1759-7714.13237
18. Campos MO, Bonamigo EL, Steffani JA, Piccini CF, Caron R. Testamento vital: percepção de pacientes oncológicos e acompanhantes. *Bioethikos* [Internet]. 2012 [acesso 18 set 2023];6(3):253-9. Disponível: <https://bit.ly/3scc6gv>
19. Sung H, Ferlay J, Siegel RL, Laversanne M, Soerjomataram I, Jemal A, Bray F. Estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA Cancer J Clin* [Internet]. 2021 [acesso 18 set 2023];71(3):209-49. DOI: 10.3322/caac.21660
20. Serey K, Cambriel A, Pollina-Bachellerie A, Lotz JP, Philippart F. Advance directives in oncology and haematology: a long way to go –a narrative review. *J Clin Med* [Internet]. 2022 [acesso 18 set 2023];11(5):1195. DOI: 10.3390/jcm11051195
21. Comin LT, Panka M, Beltrame V, Steffani JA, Bonamigo EL. Percepção de pacientes oncológicos sobre terminalidade de vida. *Rev. bioét. (Impr.)* [Internet]. 2017 [acesso 18 set 2023];25(2):392-401. DOI: 10.1590/1983-80422017252199
22. Brasil. Ministério da Saúde. Resolução nº 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, nº 225, p. 276, 23 nov 2018 [acesso 18 set 2023]. Seção 1. Disponível: <https://bit.ly/3s50Rqm>
23. Andrés-Pretel F, Navarro Bravo B, Párraga Martínez I, de la Torre García M, Jiménez del Val M, López-Torres Hidalgo J. Conocimientos y actitudes de los mayores hacia el documento de voluntades anticipadas. *Gac Sanit* [Internet]. 2012 [acesso 18 set 2023];26(6):570-3. DOI: 10.1016/j.gaceta.2011.12.007
24. Álvarez Ospina MB. El documento de voluntades anticipadas como expresión del principio bioético de autonomía: un estudio empírico en los departamentos de medicina interna [tese] [Internet]. Murcia: Universidad de Murcia; 2021 [acesso 18 set 2023]. Disponível: <https://bit.ly/3QwtKoD>
25. Zheng RJ, Fu Y, Xiang QF, Yang M, Chen L, Shi YK *et al.* Knowledge, attitudes, and influencing factors of cancer patients toward approving advance directives in China. *Support Care Cancer* [Internet]. 2016 [acesso 18 set 2023];24(10):4097-3. DOI: 10.1007/s00520-016-3223-1
26. España. Ministerio de Sanidad. Registro Nacional de Instrucciones Previas. Instituto Nacional de Gestión Sanitaria [Internet]. 2022 [acesso 18 set 2023]. Disponível: <https://bit.ly/3Rc1Oa8>
27. Abellán Salort JC. Directrices anticipadas de voluntad en España: contexto y perspectivas. In: Dadalto L, coordenadora. *Bioética e diretivas antecipadas da vontade*. Curitiba: Prismas; 2014. p. 8.
28. Cappell K, Sundaram V, Park A, Shiraz P, Gupta R, Jenkins P *et al.* Advance directive utilization is associated with less aggressive end-of-life care in patients undergoing allogeneic hematopoietic cell transplantation. *Biol Blood Marrow Transplant* [Internet]. 2018 [acesso 18 set 2023];24(5):1035-40. DOI: 10.1016/j.bbmt.2018.01.014
29. Moraes LJA, Trevisan G, de Carvalho D, Steffani JA, Bonamigo EL. Percepção de estudantes e médicos sobre autonomia na doação de órgãos. *Rev. bioét. (Impr.)* [Internet]. 2020 [acesso 18 set 2023];28(1):58-68. DOI: 10.1590/1983-80422020281367
30. Hubert E, Schulte N, Belle S, Gerhardt A, Merx K, Hofmann WK *et al.* Cancer patients and advance directives: a survey of patients in a hematology and oncology outpatient clinic. *Onkologie* [Internet]. 2013 [acesso 18 set 2023];36(7-8):398-402. DOI: 10.1159/000353604

31. Fusculim AR, Guirro UBP, Souza W, Corradi-Perini C. Diretivas antecipadas de vontade: amparo bioético às questões éticas em saúde. *Rev. bioét. (Impr.) [Internet]*. 2022 [acesso 18 set 2023];30(3):589-97. DOI: 10.1590/1983-80422022303552PT
32. Lima JS, Lima GSR, Lima SISR, Alves HKL, Rodrigues WF. Diretivas antecipadas da vontade: autonomia do paciente e segurança profissional. *Rev. bioét. (Impr.) [Internet]*. 2022 [acesso 18 set 2023];30(4):769-79. DOI: 10.1590/1983-80422022304568PT

**Christiane Veigas Pepes** – Undergraduate – chrisvpepes@gmail.com

 0000-0003-2146-8596


**Mariane Veigas Pepes** – Undergraduate – mari.veigas@yahoo.com

 0000-0002-5468-2428


**Janaína Neuhauser** – Undergraduate – jananeu@hotmail.com

 0000-0002-1279-0092

**José Carlos Abellán Salort** – PhD – jc.abellan.salort@gmail.com

 0000-0002-4470-4646

**Jovani Antônio Steffani** – PhD – jovani.steffani@unoesc.edu.br

 0000-0002-0914-7434

**Elcio Luiz Bonamigo** – PhD – elcio.bonamigo@unoesc.edu.br

 0000-0002-0226-7070

#### Correspondence

Elcio Luiz Bonamigo – Rua Treze de Maio, 314, sala 21 CEP 89600-000. Joaçaba/SC, Brasil.

#### Participation of the authors

Christiane Veigas Pepes and Mariane Veigas Pepes participated in the design of the research project, data collection, data analysis, and writing of the article. Janaína Neuhauser participated in data collection, data analysis, and writing of the article. José Carlos Abellán Salort collaborated with the data analysis and writing of the article. Jovani Antônio Steffani worked on project design, data analysis, and writing of the article. Elcio Luiz Bonamigo supervised the research and participated in all phases of writing the article. All authors approved the final version for publication.

**Received:** 1.5.2023

**Revised:** 9.18.2023

**Approved:** 10.9.2023