Perception and Expectations of Cancer Patients about the Anticipated Directives of Will

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Percepção e Expectativas de Pacientes com Câncer acerca das Diretivas Antecipadas de Vontade Percepción y Expectativas de los Pacientes con Cáncer sobre las Directrices de Voluntad Anticipadas

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ABSTRACT

Introduction: Anticipated Directives of Will is a document that allows patients to register previously and clearly expressed wills about care and treatments they want, or not, to receive in a situation of inability to express their will. **Objective:** Assess the perception and expectations of cancer patients about the concept and applicability of the Anticipated Directives of Will. **Method:** Descriptive, quantitative approach and cross-sectional study carried out with 346 patients from a reference hospital in oncology in the city of Recife-PE. The data were collected through the application of the game "Cards on the Table" (Go Wish*) and a questionnaire, according to the Likert-scale (degree of disagreement or agreement, from 0 to 10). **Results:** The mean of the knowledge of the term "Anticipated Directive of Will" was 0.64 points among patients. After explaining its meaning, the mean of the intent to prepare was 8.58 points. The mean acceptance among patients was 9.42 points for the creation in the Brazilian legislation and 9.64 points for the implantation in the hospital where they were hospitalized. **Conclusion:** In the perception of these patients, although little known, the advance directives have shown to be an instrument capable of preserving their dignity and autonomy. Patients showed interest both in their elaboration and in their applicability, however, they expect to receive more information and guidance from health professionals.

Key words: advance directives; personal autonomy; terminally ill; bioethics; neoplasms.

RESUMO

Introdução: Diretiva Antecipada de Vontade é um documento que permite registrar desejos prévios e expressamente manifestados pelo paciente sobre cuidados e tratamentos que desejam, ou não, receber em uma situação de incapacidade de expressar sua vontade. Objetivo: Avaliar a percepção e as expectativas de pacientes com câncer acerca do conceito e aplicabilidade das Diretivas Antecipadas de Vontade. Método: Estudo descritivo e transversal, de natureza quantitativa, realizado com 346 pacientes de uma instituição hospitalar de referência em Oncologia no município de Recife-PE. Os dados foram coletados por meio da aplicação do jogo "Cartas na Mesa" (Go Wish®) e de um questionário, desenhado segundo a escala numérica de Likert (grau de discordância ou concordância, de 0 a 10). Resultados: O conhecimento do termo "Diretiva Antecipada de Vontade" alcançou apenas a média de 0,64 pontos entre os pacientes. Após a explicação de seu significado, a intenção de elaboração obteve média de 8,58 pontos. A média de aceitação entre os pacientes foi de 9,42 pontos para implantação na legislação brasileira e 9,64 pontos para implantação na instituição hospitalar onde estavam internados. Conclusão: Na percepção desses pacientes, embora pouco conhecidas, as diretivas antecipadas se mostraram um instrumento capaz de preservar sua dignidade e autonomia. Os pacientes demonstraram interesse tanto por sua elaboração quanto por sua aplicabilidade, no entanto, esperaram receber mais informações e orientações dos profissionais em relação a essa temática. Palavras-chave: diretivas antecipadas; autonomia pessoal; doente terminal; bioética; neoplasias.

RESUMEN

Introducción: La Directiva de Voluntad Anticipada es un documento que permite registrar deseos, expresados previa y expresamente por el paciente, sobre los cuidados y tratamientos que quiere, o no, recibir en una situación de incapacidad para expresar su voluntad. Objetivo: Evaluar la percepción y las expectativas de los pacientes con cáncer sobre el concepto y aplicabilidad de las Directrices Anticipadas de Voluntad. Método: Estudio descriptivo y transversal de carácter cuantitativo, realizado con 346 pacientes de un hospital de referencia en oncología de la ciudad de Recife-PE. Los datos fueron recolectados mediante la aplicación del juego "Cartas sobre la Mesa" (Go Wish®) y un cuestionario, según la escala numérica Likert (grado de desacuerdo o acuerdo, de 0 a 10). Resultados: El conocimiento del término "Directiva de voluntad anticipada" alcanzó sólo un promedio de 0,64 puntos entre los pacientes. Tras explicar su significado, la intención de obtener una media de 8,58 puntos. La aceptación media entre los pacientes fue de 9,42 puntos para la implantación en la legislación brasileña y de 9,64 puntos para la implantación en el hospital donde fueron hospitalizados. Conclusión: En la percepción de estos pacientes, aunque poco, como directivas anticipadas representan un instrumento capaz de preservar su dignidad y autonomía. Los pacientes mostraron interés tanto en su evolución como en su aplicabilidad, sin embargo, agregando más información y orientación de los profesionales que atienden un tema.

Palabras clave: directivas anticipadas; autonomía personal; enfermo terminal; bioética; neoplasias.

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INTRODUCTION

The Anticipated Directives of Will (ADW) appear in the scenario of populational ageing, increase of cases of chronic-degenerative diseases and development of advanced technological resources able to prolong the lifetime of individuals even with poor prognosis. A written document in which a lucid and independent individual says what it wishes to maintain the autonomy in situations of life terminality and inability to express itself¹⁻³.

Conceptually, there are two types of ADW: living will, a written document in which a person says what its wills are if it is unable to communicate them and the lasting power of attorney for a proxy to act on its behalf. Typically, ADW are called living will, biological will or anticipated will that are used as synonyms, although they are different^{1,4}.

The living will was created in USA in 1967 as a document ensuring the patient the right to die by its own will yet unable to give its consent⁵. The first United States law granting persons the right to refuse in advance to continue living through medical technology appeared in California in 1976. In 1991, the publication of the Patient Self-Determination Act (PSDA)⁶ formalized the concept of anticipated directives and required that all hospitals, health organizations and others are enforced to provide written guidelines and educate professionals and ask the individual whether it has ADW or inform it is entitled to have one.

Nowadays, Spain and Portugal have their own laws about the practice of ADW^{7,8}. The Commonwealth of Puerto Rico was the first to legislate on that matter, in addition to Argentine and Uruguay⁹. Although no specific legislation exists in Brazil, this document is valid because integrative interpretation of the constitutional and infraconstitutional rules grants support to validate it in the legal system as the constitutional principles of the Dignity of the Human Being (art. 1st, III), of the Autonomy (implicit principle in article 5th) and prohibition of unhuman treatment (article 5th, III), and article 15th of the Civil Code which determines that nobody can be compelled to submit to life-threatening medical treatment or surgery¹⁰⁻¹².

The Brazilian Federal Council of Medicine (CFM) approved Ordinance 1,995 in August 2012¹³ acknowledging ADW as the right the patient has of expressing its will about medical treatments and assign proxies for that purpose. It collaborated to stimulate the debate about the necessity of legislative ruling on ADW¹⁴.

The Ordinance addresses ADW as a list of anticipated wills expressly manifested by the patient about treatments and care it wants or not to receive when it is unable to express its will freely and autonomously. It defines criteria that any individual can determine with its physician about what the terminal therapeutic limits are – since of legal age and fully conscious. The CFM concluded that a statement made by the patient to the physician is enough and the physician should include in the chart its decisions without signatures or witnesses; also, the physician may disregard the ADW whether in disagreement with the Medical Ethical Conducts¹³.

After CFM approved the Ordinance the practice is in force in Brazil¹². Still, a Senate Bill number 149 of 2018¹⁵ about ADW and associated health treatments is being discussed. It addresses the possibility of every individual of legal age and able to make a statement to express in advance its will of submitting or not to health treatment if with advanced disease or affected by an incurable or severe illness.

ADW are meant to protect the patient's autonomy, mostly. The principle of human autonomy establishes the respect to the freedom and ability of managing and conducting its own life based in choices and options respecting its values and beliefs. Thus, ADW emerged to reinforce the practice of freedom and self-determination of the human being under the belief that its autonomy will be respected through this document in relation to the treatment it and/or its assigned proxy^{16,17} wishes.

The benefits are not only to the patient who will have its will ensured but to its family while minimizing the burden of deciding which end-of-life conducts will be taken. It will also be advantageous for healthcare professionals mainly those involved in the dying and death process due to the support and safety it grants to act while the patient's wills are being respected^{7,18,19}.

Nevertheless, the theme is quite controversial because of poor knowledge about what an ADW is, its applicability and fear of legal processes^{20,21}. Internationally, the main obstacles are related to the difficulties the patients have in anticipating and preparing their will, worsening of the health condition, among others, as problems of talking about death, change of opinions and proxies who not always are the best translators of the patient's interests²²⁻²⁴. In despite of this, its use is increasing, moving from debate to effective practice^{18,25}.

Although life-threatening diseases are found in every medical area, patients with cancer are among those who live more constantly the finitude. Neoplasms are the main causes of world mortality, it is an important public health issue. Patients with cancer face the incurability of the disease and not being able to express their will in end-of-life. Thus, ADW is a remarkable achievement to strengthen its autonomy and safety. The present study aims to evaluate the perception and expectations the

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METHOD

Quantitative, descriptive, cross-sectional study with patients of a referral oncology hospital in the city of Recife-PE with data collected from March to June 2020. The minimum study sample of 346 individuals was estimated from the institution's Cancer Hospital Register and based in sampling calculation with 5% of margin of error and confidence level of 95%.

Participants were selected from simple random sample, consisting of patients with cancer, older than 18 years with recent diagnosis or in disease-modifying therapy, regardless of tumor site who were at the institution in the days and hour the data were collected, admitted or in outpatient treatment; illiterate and/or patients with spatial and temporal disorientation were excluded.

The game Go Wish® of the Brazilian Society of Geriatric and Gerontology (SBGG)³¹ and a Likert-type questionnaire based in Campos et al.⁴, modified to adjust to the patients experience at the institution were utilized as research tools; it has 5 sociodemographic questions and data about ADW with 13 Likert-scale³² questions. All the questions were addressed and presented in the tables, portraying the knowledge, interest and acceptability the patients have about the theme. The changes included synonyms of the description of the document, items about concurrence with its implementation at the institution and end-of-life wills. Euthanasia, dysthanasia and orthothanasia were excluded because they were off the study scope.

The Likert-scale³² measures attitudes in opinion studies, requiring participants to tell their level of agreement or disagreement in relation to a certain attitude. Numbers are attributed to their opinion, the highest reflect agreement and the lowest, disagreement with 10 as maximum value for fully agreement and 0, the lowest for fully disagreement.

The objectives and methodology were explained to every participant who signed the Informed Consent Form (ICF) after deciding to join the study. Next, the Go Wish game was conducted and in the end the questionnaire was applied.

SBGG authorized the game Go Wish as research tool with 36 cards portraying hypothetical situations about end-of-life whose goal is to modify the scenario of uneasiness to talk and think about death and promote the dialogue about the theme³³. It was utilized in the study to facilitate the conversation about ADW and stimulate the reflection about end-of-life care and preferences. The application in the study was modified to improve the dynamics, regardless of the manual of instructions. Every player should form three stacks representing "high priority", "medium priority" and "low priority". The cards were shuffled and offered to the patients who pulled out six cards, read them and put in one of the three stacks.

Frequency, mean, mode and standard deviation were calculated for the responses to analyze and interpret the results utilizing the statistical descriptive method with the software Statistical Package for the Social Sciences (SPSS) version 26.

The Institutional Review Board (IRB) of "*Hospital de Câncer de Pernambuco*" approved the study, report number 3,850,965 (CAAE 26742219.5.0000.5205).

RESULTS

Of the 346 participants, 228 (65.9%) were diagnosed with the oncologic disease between 0 and 12 months from the moment of the collection, with predominance of females with 67.3% (n=233), mean age of 62.5 years, ranging from 18 to 77 years but mostly in the age range of 41-50 years. Catholicism was the prevalent religion for 51.2% (n=177) and incomplete elementary school for 39.3% (n=136) (Table 1).

 Table 1. Sociodemographic characteristics of the study sample.

 Recife-PE, 2021

Variables	Categories	Ν	%
Time of	0 to 12 months	228	65.9
diagnosis	13 to 24 months	49	14.2
	25 to 36 months	28	8.1
	More than 36 months	41	11.8
Sex	Female	233	67.3
	Male	113	32.7
Age	18 to 30 years	72	20.8
	31 to 40 years	52	15
	41 to 50 years	88	25.4
	51 to 60 years	76	22
	More than 61 years	58	16.8
Religion	Catholic	177	51.2
	Evangelic	124	35.8
	Spiritualist	12	3.5
	Agnostic	28	8.1
	Atheist	5	1.4
Education	Elementary incomplete	136	39.3
	Incomplete High	31	9
	school	119	34.4
	Complete High	60	17.3
	school		
	University or higher		

Table 2 presents the results of the Likert-scale responses to the questionnaire, revealing poor previous knowledge the interviewee has about the term Anticipated Directives of Will or its synonyms with mean of responses of 0.64, being 0 the most frequent, that is, complete unawareness.

When asked whether they would like to have more information and guidance about ADW, the prevalent response was 10, full agreement and the mean was 9.38. Also, it was asked whether the patient would draft an ADW and of the 346 interviewees, 283 (81.8%) attributed 10 in the Likert-scale, equal to the mode with mean of 8.58.

Table 1 shows the agreement that once implemented, ADW should be strictly respected. The mean of the patients' responses was 8.15 and mode of 10 (66.8% of the interviewees).

The tool presented two hypothesis in order to know the patients' opinion about the implementation and use of ADW: create ADW legislation and implementation at the hospital where the patient was hospitalized. The patients have a positive perception about the implementation of ADW, the mode was 10 for both hypotheses and despite the agreement for the two, there was preference to implement it at the institution, with mean of 9.64 as seen in Table 2, with more homogeneity of responses with low standard deviation for the results.

The interviewees were asked about the positive and negative aspects of the implementation of ADW. It represents benefits as preservation of dignity and respect to values and autonomy, more safety in relation to end-of-life conducts as the data in Table 2 reveal with mean of 9.71. 47.7% (n=165) of the patients thought that the application of ADW could be limited by factors as education, beliefs and cultures while 42.2% (n=146) fully disagreed with this with standard deviation of 4.75. 87.3% (n=302) fully disagreed to the possibility that ADW would affect care and/or fight for life and denied any type of negative influence on motivational factors. The mean was 0.82 with mode of 10.

When asked whether they have already spoken with anyone about their end-of-life wills, the most common response was 0, fully disagreement, mean of 3.22. The same response was given to the question about the registration of these wills, mean of 2.54, with standard deviation of 4.65 and 4.36, respectively. Table 3 shows these responses.

In relation to assigning a proxy to act on their behalf to deal with undesired factors, the mean of responses was 9.54, possibly showing that for most of them, no doubts remain because the mode was 10 with standard deviation of 2.16. The values were similar for proxies already assigned, with mean of 9.10 and mode of 10 (91% of the interviewees) as seen in Table 3.
 Table 2. Perception and expectations about Anticipated Directives of

 Will according to Likert-scale. Recife-PE, 2021

Variables	Mean	Standard Deviation	Mode
Knowledge of the terms "Anticipated Directives of Will", "Living Will" or "Biological Will"	0.64	2.38	0
Would like more information and guidance about the possibility of drafting the Anticipated Directives of Will	9.38	2.02	10
Would you draft your own Anticipated Directives of Will?	8.58	3.18	10
Do you believe that the Anticipated Directives of Will should be followed strictly?	8.15	2.83	10
Do you agree with the creation of a Brazilian legislation of Anticipated Directives of Will?	9.42	1.87	10
Do you agree with the implementation of Anticipated Directives of Will at the institution where you are currently hospitalized?	9.64	1.58	10
The Anticipated Directives of Will promote the preservation of the dignity, respect to values and autonomy and safety in relation to end-of-life conducts	9.71	1.34	10
Education, beliefs and culture can limit the applicability of Anticipated Directives of Will	5.34	4.75	10
The Anticipated Directives of Will can affect care and/or fight for life	0.82	2.32	0

Table 3. Perception	of the	respondents	about	end-of-life	wills	and
proxies. Recife-PE, 20	21					

Variables	Mean	Standard Deviation	Mode
Have you ever spoken with anyone about end-of-life wills?	3.22	4.65	0
Have you ever registered these wills?	2.54	4.36	0
Necessity of assigning a proxy for undesired events	9.54	2.16	10
Possible proxy, if needed	9.10	2.86	10

Chart 1 portrays the priority of hypothetical situations about the process of dying according to six of the 36 cards of the Go Wish which were selected through a simple random sample.

High priority predominated among the results of classification for all the cards, with absolute priority (100%) for cards 4 and 12 which addressed the respect to the will of having a bond of trust and attention with the healthcare team and preservation of dignity.

The context of cards 16 and 32 consists in the family wish of respecting the patient's wills and participation in its care with low and mid priority -2.1% for card 16- and the same priority for card 32. Card 21 addresses the wish of not being a burden for the family with low priority (17%) as opposed to 70.2% for those who classified as high priority. Card 20 expresses the wish of not being alone in death, with 83% as high priority, 10.6%, medium priority and 6.4% as low priority.

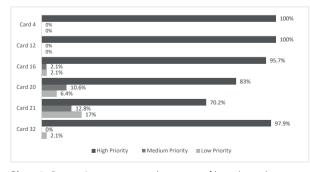


Chart 1. Patients' perception on the priority of hypothetical situations about end-of-life in six cards: I want a doctor I trust and heedful nurses (card 4); I want to protect my dignity (card 12); I want my family to respect my will (card 16); I don't want to die alone (card 20); I don't want to be a burden to my family (card 21); I want to have a voice in planning my care (letter 32). Recife-PE, 2021

DISCUSSION

The moment to discuss ADW may impact its acceptance and effect. Preferentially, the discussions should occur during the encounters conducted by a knowledgeable and skilled professional to respond to the questions and detect patients' uneasinesses³⁴. In order to evaluate the perception and expectations about the concept and applicability of the document in advance, patients with recent diagnoses or in surgical, chemotherapy or radiotherapy treatment were approached. Two hundred and twenty-eight (65.9%) of the 346 participants were diagnosed with oncologic diseases between 0 and 12 months from the moment of collection.

Few Brazilian studies addressed the patients' perspectives about ADW. The results of a study by Campos et al.⁴ with 110 patients with cancer indicated they were unaware about the theme, 0.13 in the Likert-scale. With a larger sample of 346 patients, the present study reached a mean of responses of 0.64, being 0 the most frequent, that is, total unfamiliarity of the synonyms, corroborating the referenced study.

Contrary to these studies, a research of 1991 with 75 American patients, the country where the living will was included in the 1990 federal law, found that only 11 (15%) had no knowledge about the terms³⁵.

A limiting factor to know and apply ADW is the difficulty of communication as Cogo et al.³⁶ concluded in a study with nurses, residents and family caretakers of patients without possibility of cure in a region of Rio Grande do Sul. The difficulty healthcare professionals have in dealing with end-of-life impacts the communication of this condition to the patients and family.

Some authors point out the poor undergraduate education to justify why health professionals are unprepared to cope with end-of-life and probably fail to discuss and help patients to draft documents expressing their wills^{27,37,38}. The study of Cogo et al.³⁶ shows the necessity of health professionals to understand what ADW is but also to attempt to make it happen with supportive information and clarification. This limitation was also perceived by the patients of the current study who feel themselves uninformed and wished to have more information and guidelines about the concept and how to draft the document.

After being informed about what the document is, the mean of intention of the patients to draft the ADW in the study of Campos et al.⁴ increased to 9.56. Similarly in the present study, 81.8% (283) of the patients scored 10 to the wish to draft their own living will after clarifications about its goal with mean of 8.58.

Soon after the issue of PSDA⁶ in the USA a study with two methods of intervention was carried out; the first group was handed over a leaflet with information about ADW and the second group, a leaflet and continuous discussions conducted by the physician. 61% of the patients of the first group (only the leaflet) discussed with the family the care they would like or not to receive in possible end-of-life. For the second group (leaflet and discussions), 70% were interested in discussing the living will, showing that the intervention was more effective³⁹. The results were quite similar indicating that good communication by skilled professionals to promote the ADW is important.

The patients investigated had a positive perception about the creation of specific legislation in the Brazilian legal system with mean of agreement of 9.2. Quite similar to the results encountered by Campos et al.⁴, whose mean of acceptance was 9.56, making clear the relevance of the legal infrastructure.

The agreement for the implementation of ADW in the institution where they are hospitalized was similar, preferring the creation at the institutional level rather than legislative with mean of 9.64 and more homogeneity of responses with low standard deviation. In addition, great part of the patients assigned high priority to participate of the planning of their own care as suggested in card 32 when data were collected.

A study conducted in Geneva found lower anxiety and depression rates in patients with advanced oncologic disease who drafted an ADW; their motivation was to broaden their autonomy, improve the communication with caretakers and health professionals and certainty that their preferences would be respected⁴⁰.

There are enough indication that allow to uphold the respect of the patient's autonomy, which is a core ethical principle of ADW. One of the positive aspects is that most of the study sample fully agree that with the implementation of the document, dignity will be secured and respect to values and autonomy will be encouraged in addition to potential safety in relation to the conducts to be taken in end-of-life, corroborating the study of Pautex et al.⁴⁰.

When asked about the negative aspects, there was more dispersion with standard deviation of 4.75 because part of the respondents thought there could be limitations of application due to education, beliefs and culture, which was found in the study of Ohr et al.²⁵. 87.3% (n=302) of the interviewees strongly denied any kind of negative influence this document might have over motivational factors if care and/or fight for life could be possibly neglected with ADW.

Conversely, for the nurses of a study by Cogo et al.¹, the discontinuation of the treatment in respect to the ADW could demotivate the care to the patient. Another negative topic found is fear the professionals may have of legal penalties due to the lack of legislation supporting the conduct. Similarly, other studies reported the medical fear of being sued for meeting the patients will^{12,41}.

In addition, a study revealed that few individuals wished to record their preferences for specific medical treatments and demands that needed to be followed *ipsis litteris* near to death⁸. Given this, it is a limitation of the document. However, for the reality of the present study, this limit was not seen; the participants revealed they wished the ADW to be followed strictly once implemented with mean value of 8.15 in the Likert-scale and mode of 10 (66.8% of the interviewees).

The same authors concluded that there is an intersection among the arguments in favor and against ADW; the document should be part of a process that favor an open dialogue to reflect the actual needs, beliefs, values and goals of care and patient's preferences⁸ like in other studies^{21,42} showing still the necessity of focus by the CFM and legislators and education of health professionals, reinforcing the idea that it is not enough for the patient to have a guidance if the professionals fail to accept its will.

The patients with cancer investigated classified the desire to have a bond of trust and care with the health team as high priority, this concern is reasonable in understanding that the participation of the patients in the treatment leads to better outcomes within the old belief that a good and amenable relation among the team and the patient is the foundation of a better healthcare continuously offered to an ill person⁴³.

The communication among patients and their families about ADW is quite important. The wish to have their families to respect their wills was assigned high priority for 95.7% in this study. Former studies, however, indicated adherence issues of expressing the will because family members or surrogates do not know how to act due to poor communication among them^{1,44,45}.

Reinforcing the communication gap and the taboo of discussing death and dying, the patients investigated reported nearly full disagreement when they were asked whether they have spoken with anyone about their endof-life wills or their record. Similar to the patients of the study of Scottini et al.²¹, where 69% said that no record has ever been made of their end-of-life wills.

Kübler-Ross⁴⁶ argues that death is part of life and gives meaning to human existence. Kovács⁴⁷ affirmed that humanized death with the presence of family and friends should be reclaimed, in respect to the patient's beliefs and values concurring with the high priority patients of this study assigned to the wish of not wanting to die alone and not be a burden to their family.

A USA study affirms that 39.4% of the individuals who draft some document addressing medical decision-

making prefer the living will and the lasting power of attorney in the same document while 21.3%, only the lasting power of attorney and 6.8%, the living will⁴⁸. When asked about the necessity to assign a proxy to deal with unexpected events, most of them agreed and said that they already have a person in mind, if the case, even if they had ever discussed their wills.

It is quite common to assign a proxy who does not correctly translate the patient's interests. A study whose goal was the surrogate decision-making concluded that, in addition to depending on the patients' wills, the surrogate ponder other factors as their own wishes, interests, religious beliefs and past experiences. This modality of decision-making is quite more complex than the patient's⁴⁹.

Studies suggest awareness campaigns about the importance for the population to respect their family wills to avoid conflicts between the ADW and the family and improve this scenario. As this is gradual, it is known that guidelines offered by healthcare professionals are the best way to minimize the conflicts of wills immediately⁴².

CONCLUSION

ADW are a tool able to protect the dignity and autonomy of the patients with cancer as they perceive it. They believe the document allows their wills to be met and ensures safety in relation to end-of-life conducts.

On the other side, it was made clear that unawareness is the main reason of poor responses in relation to ADW. In the patients view, guidelines offered by healthcare professionals could have a considerable impact on its applicability and potentially the acceptance for its elaboration. Patients expect to have more information and guidelines about the theme from the team who works with them.

Patients' expectations help to feed the debate so that not only the doctors but healthcare professionals too who care intensively and directly for those with nontherapeutic alternatives to act through multidisciplinary approach.

The study reinforces that a specific legislation could be greatly relevant for its enabling and dissemination in Brazil. Patients with cancer believe in the necessity of creating a legislation for ADW and were receptive for the implementation at institutional level which could be more effective in meeting the patients' wills if the caring team is aware of their wills.

Ultimately, it is anticipated that the study is able to help other investigations about the theme focused to its applicability because the practice is still embryonic.

CONTRIBUTIONS

Both authors contributed for the study design and/ or conception, acquisition, analysis and interpretation of the data, wording and critical review. They approved the final version to be published.

DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interests to declare.

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