

Anticipated directives and living will for terminal patients: an integrative review

Diretivas antecipadas de vontade aos doentes terminais: revisão integrativa
Directivas previas a los pacientes terminales: revisión integradora

Silvana Bastos Cogo¹, Valéria Lerch Lunardi¹

¹ Universidade Federal do Rio Grande, Department of Nursing, Postgraduate Program in Nursing. Rio Grande-RS, Brazil.

How to cite this article:

Cogo SB, Lunardi VL. Anticipated directives and living will for terminal patients: an integrative review. Rev Bras Enferm. 2015;68(3):464-74. DOI: <http://dx.doi.org/10.1590/0034-7167.2015680321i>

Submitted: 01-21-2015 Approved: 05-08-2015

ABSTRACT

Objective: characterizing the national and international scientific literature about the advanced directives of living will as applied to the terminally ill patient. **Method:** integrative review considering the articles published in Portal Capes, SciELO, LILACS, MEDLINE, Journal of Bioethics and Bioethikos, with the descriptors: Advanced directives, Wills regarding life and Advance Directives, Living Will and Terminally Ill, totaling 44 articles submitted to content analysis. **Results:** three categories emerged: Students and professionals facing the advance directives of living will: Perceptions, opinions and practices; Patient's receptivity to the Advance Directives of Living Will; The family facing the advance directives of living will. **Conclusion:** the relevance of the topic became evident as a guarantee of respect for the dignity and autonomy of the patient, as well as to reduce ethical conflicts faced by families and health professionals facing care at the end of life.

Keywords: Advance Directives; Terminally Ill; Living Will; Personal Autonomy.

RESUMO

Objetivo: caracterizar a produção científica nacional e internacional sobre as diretivas antecipadas de vontade aplicadas ao doente terminal. **Método:** a revisão integrativa, incluindo os artigos publicados no Portal Capes, SCIELO, LILACS, MEDLINE, Revista de Bioética e Bioethikos, a partir dos descritores: Diretivas antecipadas, Testamentos quanto à vida, *Advance Directives*, *Living Will* e *Terminally Ill* totalizando 44 artigos submetidos à análise de conteúdo. **Resultados:** emergiram três categorias: Estudantes e profissionais frente às diretivas antecipadas de vontade: percepções, opiniões e condutas; Receptividade dos pacientes às diretivas antecipadas de vontade; A família diante das diretivas antecipadas de vontade. **Conclusão:** evidenciou-se a relevância do tema como garantidor do respeito à dignidade e à autonomia do doente, bem como para a redução dos conflitos éticos enfrentados pelos familiares e profissionais da saúde frente aos cuidados em final de vida.

Descritores: Diretivas Antecipadas; Doente Terminal; Testamentos Quanto à Vida; Autonomia Pessoal.

RESUMEN

Objetivo: caracterizar la literatura científica nacional e internacional acerca de las directivas anticipadas de voluntad aplicadas a los enfermos terminales. **Método:** la revisión integradora fue el método utilizado, teniendo en cuenta los artículos publicados en el Portal Capes, SciELO, LILACS, MEDLINE, Revista de Bioética y Bioethikos, con los descriptores: Directivas anticipadas, Testamentos en cuanto a la vida y *Advance Directives*, *Living Will* e *Terminally Ill* con 44 artículos sometidos al análisis de contenido. **Resultados:** surgieron tres categorías: Estudiantes y profesionales frente a las directivas anticipadas de voluntad: percepciones, opiniones y conductas; La receptividad de los pacientes a las directivas anticipadas de voluntad; La familia frente a las directivas anticipadas de voluntad. **Conclusion:** és evidente la importancia del tema como garantía del respeto de la dignidad y la autonomía del paciente, así como para reducir los conflictos éticos que enfrentan las familias y los profesionales de salud frente a la atención al final de la vida.

Palabras clave: Directivas Anticipadas; Enfermo Terminal; Voluntad em Vida; Autonomía Personal.

CORRESPONDING AUTHOR Silvana Bastos Cogo E-mail: silvanabastoscogo@yahoo.com.br

INTRODUCTION

The ability to heal a variety of illnesses has increased the life expectancy of the population, due to the availability of resources that allow for the reversibility of diseases once considered incurable, such as cancer, resulting in an increase in lifespan. However, this has increased the research by the health care services to obtain the cures, even when available resources are ineffective and the healing possibilities are no longer possible⁽¹⁾, resulting in the extension of human suffering, with disrespect to human dignity and to autonomy of the patient regarding the decision-making process about life, especially in the terminal phase.

Respect for autonomy⁽²⁾ implies knowing about the rights to have an opinion, to make choices and to act with the basis of personal beliefs and values. To disrespect the autonomy of an individual means treating the patient as only a means, in accordance with the objectives of the others. This attitude constitutes a moral violation, because autonomous individuals are an ends in themselves, able to determine their own destinies.

Considering these aspects, the Advance Directives and Living Will (ADLW), which have received distinctive terms, among them: Living will, Testament, advance treatment guidelines, advance declaration of living will, advanced treatment declaration and prior declaration of the living will of the terminal patient. Some of these expressions are implemented or translated terms used in foreign laws or contexts [from a Brazilian perspective], such as living will and advance directives, in the United States of America (USA); biological testament, in Italy, and anticipated wishes, in Spain⁽³⁾.

In conceptual terms, the ADLW covers two types: the living will (also named as the prior declaration of the living will of the terminal patient) and the durable power of attorney. The living will is a document by which a person can register, in accordance with their wishes, which treatments to be submitted to in the case of an incurable disease, to ensure the patients right to die with dignity, in accordance with their personal views⁽⁴⁾. The durable power of attorney refers to the appointment of one or more attorneys, with an in-depth knowledge of the patient, with the ability to identify the patient's wishes⁽⁴⁻⁵⁾, when the patient is unable to express his/her wishes. In addition it is salient to point out that there can be a concurrency between the living will and the durable power of attorney, submitted as a single document⁽⁴⁾. Based on the above, although there is a clear conceptual adaptation of the terminologies described, the use of the term living will – commonly used in Brazil – is sometimes criticized due to its sense of will as an instrument corresponding to a unilateral willful act being only effective post-mortem⁽⁵⁻⁶⁾. In Brazil, the used term, recently approved by the [Brazilian] Federal Council of Medicine (CFM), through Resolution 1,995/12⁽⁷⁾, is the ADLW, understood as the given wishes, previously set out by the patient, about the care and treatments that they wish to receive, or not, at the time they become unable to express their wishes freely and autonomously. The resolution recognizes the rights of the patient to refuse futile treatments also known

as extraordinary treatments, these being treatments that target only the extension of biological life without ensuring the quality of that life⁽⁸⁾.

So, to ensure that the patient's autonomy is respected, the resolution demystifies the medical power-centric culture and paternalism that reduces the individual to simply a patient that must wait resigned and submissively whilst deliberations about his/her life are made by others, without which they can either be treated or not and have no input in what kind of practices they are willing to accept⁽⁹⁾. Thereby, the ADLW represents an exercise of the right to liberty, since it is an area in which the individual has the ability to take personal decisions, free from interference, either from doctors, family or any other person or institution that wishes to impose their own volition⁽¹⁰⁾.

When considering the relevance of the subject about assistance to the terminally ill, their families and health professionals, especially nurses, who will help in the resolution of the ethical dilemmas arising from the decisions that involve the assistance provided to those who have no prospects of a cure, in the Brazilian scenario, there is an undeniable contribution of international studies that seek to disseminate publications, in particular in the areas of health, bioethics and law, to understand this theme. Based on the foregoing, the guiding question in this review was: What knowledge is being produced in Brazil regarding the ADLW, and what knowledge is being applied to the terminally ill in the international scope? To this end, we aimed to analyze the scientific literature regarding advance directives both in Brazil and in other countries, as they applied to the terminally ill.

METHOD

To achieve the aim of this study, we opted for an integrative literature review, which made it possible to gather and synthesize results from multiple studies published about the scope of the theme in a systematic and orderly way, contributing to a deepening of the knowledge regarding the investigated subject. It was developed in six steps: establishment of the topic and research question; definition of inclusion and exclusion criteria for sample selection; categorization of studies; evaluation of the included studies; interpretation of results and finally the presentation of the review⁽¹¹⁾.

To identify publications that would compose the integrative review, an online search of bibliographic sources from the Virtual Health Library (VHL), using the databases: *Literatura Latino-Americana e do Caribe em Ciências da Saúde* (Latin American Literature and Caribbean Health Sciences) (LILACS), *Scientific Electronic Library Online* (SciELO), *Literature Analysis and Retrieval System online* (MEDLINE), IBECS-Spain and the Capes Journal Portal. The search for the publications in Brazil regarding the theme was also made in specific magazines about bioethics, including the bioethics magazines and Bioethikus, as they were the ones which presented articles on the subject of ADLW and living will.

The data survey was conducted in November 2014 in distinct ways; first, using the key words "wills related to life"

and “advance directives” referred to in Health Sciences Descriptors (DeCS) and the term “living will” to select articles produced in Brazil. In the second step, a combination of the descriptors: *advance directives and terminally ill*, and *living will and terminally ill* to carry out the selection of scientific articles with an international view.

After the search of scientific articles, a primary analysis of articles for verifying the approach with the proposed objectives was performed. So, to carry out refinement, the following inclusion criteria were defined: scientific articles that spell out the adopted methodological approach; written in Portuguese, English or Spanish without any restriction on the year of publication and related to the terminally ill or final stages of life. Articles that favored literature reviews, editorials and abstracts from conference proceedings were excluded.

The obtaining of the selected studies occurred by a careful reading of the title and summary by the first author, noting its suitability to the guiding question and to the inclusion criteria. To answer the guiding question, a data collection instrument was created, containing: year of publication, article title, research objective, methodological considerations, main results and conclusions. Finally, the articles were analyzed in their entirety and then the production of the results occurred in a descriptive manner through content analysis based on the thematic analysis model⁽¹²⁾. From the initial floating readings and the ones carried out in depth by a researcher, the units from the report text were identified, allowing for the visualization of the most significant issues in each text⁽¹²⁾. After following this methodology, the information had been grouped by similarities or dissimilarities and organized into thematic categories.

RESULTS

In the search of international the articles, using the combination of descriptors *advance directives* and *terminally ill*, 226 articles were found; of these, 179 were excluded for not being in agreement with the criteria established and 21 were excluded for being repeated in the different data bases used. Therefore 26 articles were selected. Using the descriptors *living wills* and *terminally ill*, 72 items were found; of these, 11 were excluded by virtue of repetition in the data bases and 56 were disregarded, which resulted in the analysis of five articles. Therefore, in the international scope 31 articles were found and analyzed.

When considering the descriptors “advance directives”, “wills regarding life” and the term “living will”, 85 items were found; of these, 58 were excluded and 14 were repeated. The combined search keywords using “terminally ill” was performed, but no articles were found, probably due to the lack of study regarding this theme in the country. So, from Brazilian sources, 13 articles were selected for analysis. In all, the samples from the research were made up of 44 articles.

In the international panorama, 31 articles were selected⁽¹³⁻⁴³⁾, identifying the publication of six articles from the 1990s⁽¹³⁻¹⁸⁾, 14 articles from the 2000s⁽¹⁹⁻³²⁾ and 11 articles from 2010 onwards⁽³³⁻⁴³⁾. The searches were performed in Europe^(22,25-26,28,30,33-34,37,39,41-42), South America⁽⁴⁰⁾, North America^(13-20,24,26,31,36,38) and Asia^(21,32,35,43).

The target audience of the research included doctors^(14-15,18,21,24-25,27,35,37,41,43), nurses^(15,18,25,35-37,39), health care professionals⁽³³⁾, university students^(37,42), patients^(13,16-17,19-20,25,28,30-32,36,40,43), families and those responsible for terminal patients^(17,36,38,40,43) and the general public^(22,34,43).

In the national scenario, of the 13 analyzed articles, four dealt with research involving human beings⁽⁴⁴⁻⁴⁷⁾, conducted with doctors⁽⁴⁴⁻⁴⁵⁾, oncologists, intensivists and geriatric specialists⁽⁴⁷⁾, medical students, lawyers and human rights students⁽⁴⁴⁾. We highlight that one of these studies had the objective of organizing a Brazilian advance directives policy in the country, based on a research conducted in Minas Gerais (MG)⁽⁴⁷⁾.

The three other studies, held in Santa Catarina (SC), discussed issues regarding the knowledge and adherence of the ADLW in Brazil⁽⁴⁴⁻⁴⁶⁾. The nine remaining national articles attended to questions in the area of rights, considering legislation and practicality, beyond the constitutionality and applicability within the Brazilian scene^(3,5-6,9-10,48-51). In relation to the publication years of the scientific material from Brazil, one was published in 2006⁽⁵¹⁾, one in 2009⁽⁵⁰⁾, two in 2011⁽⁴⁴⁻⁴⁵⁾, three in 2012^(6,46,49) and six in 2013^(3,5,9-10,47-48).

From the findings and analysis of the scientific publications regarding the ADLW, three category themes emerged and are presented here: Students and professionals facing the ADLW: Perceptions, opinions and conduct; Receptivity of patients to the ADLW; The family facing the ADLW.

Students and professionals facing the Advance Directives of Living Will: perceptions, opinions and conduct

In the international panorama, the research conducted with doctors, nurses, other health care and university professionals aimed to present about the perceptions, opinions and conduct in reference to the use of ADLW when applied to terminal illnesses. In the hospitals of Murcia, in Spain, in a research piece with 607 medical professionals, nurses and students, 63.3% stressed the importance of patient preferences regarding treatment and life support procedures of terminally ill patients⁽³⁷⁾. In South Korea, a survey of 303 oncologists demonstrated that 96.7% agreed with the need to fill out the ADLW⁽⁴³⁾.

In Canada, 86% of 643 doctors surveyed were in favor of its use, however, only 19% had actually discussed the ADLW with more than 10 patients, and more than half said they didn't always follow the information contained in the ADLW⁽¹⁴⁾. On the other hand, other studies indicate that approximately 90% of the doctors would attend to the advanced directives of the patient at the time that the patients were no longer able to participate in the decision making process⁽⁵²⁾. In Japan, 55% of 301 doctors approved of the use of the ADLW. However, 34% had the opportunity to discuss the living will with patients or family members after receiving the testament but did not and 69% of doctors hadn't received one⁽²¹⁾. In Pennsylvania, 282 doctors disclosed an average of 6.2 discussions per month regarding the ADLW, deeming themselves as being competent to discuss the ADLW with patients, but not managing to engage sufficiently to conduct such discussions⁽²⁴⁾.

In 1999, in the USA, a study to verify the opinions of 11 nurses and 10 doctors that took care of people at the end of

their lives revealed that doctors do not always explain clearly about the chance of survival of their patients or do not always understand their patient's wishes. In addition to this, ethical uncertainty dominated the decision-making of doctors and nurses, when faced with the possibility to assist with the death of patients, even in light of the living will⁽¹⁸⁾.

In a research project in Germany with 100 doctors, 39% of them never mentioned to patients the possibility to write an ADLW for medical care⁽²⁵⁾. In a study that estimated and compared the prevalence of the discussions about treatment and the appointment of substitute decision-makers to patients regarding the end of life in Italy, Spain, Belgium and the Netherlands, discussions between doctors and patients about treatment preferences related to the end of life had occurred with 10% of the Italians, 7% of the Spanish, 25% of the Belgians and 47% of the Dutch patients⁽⁴¹⁾.

In Canada, in a research study to discover the opinions of 643 doctors regarding when the opportunity to fill out advance directives should be offered, 96% of the doctors said it should be offered to patients with terminal illnesses, 95% for patients with chronic diseases, 85% for people with human immunodeficiency virus infections, 77% for people over 65 years of age, 43% for all adults, 40% for people admitted to hospitals for elective surgeries and 33% for people admitted in emergency situations⁽¹⁴⁾.

In Germany, in a research with doctors and nurses about the wishes of patients undergoing cancer treatment at the end of their lives, doctors rejected the proposal to start a routine discussion about advance directives with their patients, being prepared to do it only if deemed appropriate, as a result of an individual situation, in addition to the preference of delegating this initiative to other people, usually the family members of the patient⁽²⁵⁾. As a counterpoint, talk about ADLW is associated significantly to more years of post-graduation study and it was also noted that discussions about the subject at work were seen as useful to learn about care in the final stages of life. The purpose of a professional qualification can be a means of increasing the capacity of the doctors to hold conversations with patients⁽²⁴⁾.

A survey conducted in eleven US States examined the interests of 415 patients with ambulatory cardiac problems about their participation in the prior planning and their willingness to participate in educational activities about the advance directive, noted that discussions initiated by doctors occurred with 5% of the patients⁽¹⁹⁾. However, in another study, doctors had discussed the primary diagnosis with 49% of Italian, 50% of Spanish, 60 percent of Belgian and 78% of their Dutch patients. A minority of patients from all countries (10-31%), with the exception of the Netherlands (52%), had discussed treatment preferences or the idea of a named substitute⁽⁴¹⁾.

Studies^(13,17,22,28,42) have demonstrated that the practice of the ADLW happens effectively when there is adequate communication between health care professionals and the patient.

In Brazil, there is little research that addresses the ADLW and the perceptions of health care professionals about the subject. The studies that we found contributed to the understanding of professional issues related to the implementation of the ADLW, such as knowledge of the medical subject area

and of the rights in relation to the ADLW⁽⁴⁴⁾; respect for the patient's advance directives by the doctors when patients were incapacitated and unable to communicate if this demonstration constituted a valid instrument of dysthanasia inhibition⁽⁴⁵⁾; and, finally, issues related to the possibility of proposing a ADLW model for Brazil⁽⁴⁷⁾.

In a study conducted with a group of doctors, lawyers, and medical and human rights students totaling 209 subjects, approximately 29.2% of respondents had a full knowledge of the significance of the living will. As such 87.6% of respondents would choose for orthothanasia for a patient in a terminal phase of life, by failing to consider the implementation of the living will. However, faced with the possibility of implementation, the option for orthothanasia would be at the discretion of 35.9%, while the option established in the living will was pointed out to be given by 60.8% of those interviewed⁽⁴⁴⁾.

Similarly, another recent survey conducted with 100 basic care physicians, from Intensive Care Units (ICU), accident and emergency and from other specialties, found the opinions from the records of the patient's wishes through the living will and advance wishes that doctors respected them, with a score of 7.68 to 8.26 on a scale of 0 to 10. Still, they acknowledge this declaration as a useful tool for decision-making, with a rating of 7.57. In fact, such results, although quite limited considering sampling, signal an acceptance of the living will of the patient by the doctors involved in the research⁽⁴⁵⁾.

Doctors interviewed in research realized that the Resolution of the Federal Council of Medicine (Brazil) 1,995/12 did not satisfactorily regulate their role in the drafting of the ADLW, showing a need for them not to be passive in this process, offering help and offering information to the patient in the drafting of the document, to legitimize their autonomy. It is recommended that the doctor permits the patient to mention this in the ADLW, so that the medical team, if necessary, can contact them. This, however, can only be carried out with the express authorization of the doctor⁽⁴⁷⁾.

Patient's receptivity to the Advance Directives of Living Will

The ADLW can be adjusted at any time, considering that the circumstances, values and opinions can be modified, and that the patient must be offered regular opportunities to update their preferences^(28,53). To prepare the ADLW whilst thinking about the terminal state is to be a hostage of the situation, due to the difficulty in defining what is to occur in this situation. However, the intention is to prevent patients from being kept alive in a weakened and incapacitated state⁽⁵⁴⁾.

In South Korea, from 1,242 patients with cancer and 1,006 members of the general public, 93% and 94.9%, respectively, agree with the need to fill out the ADLW⁽⁴³⁾. In The United Kingdom, research conducted with 18 cancer patients found that the experience caused changes in the way in which they viewed life, in such a way that they wanted to live more in the present and not stretch out plans for the future⁽²⁸⁾. For example, the terminally ill are more likely to forgo invasive procedures for procedures that are less invasive⁽¹⁷⁾, which stresses the need for the registering of the ADLW, so that that the patient's wishes can be fulfilled and respected. In Germany, in relation

to the wishes of 100 cancer patients, it was shown that there is a preference for treatment with antibiotics and painkillers, wishing to significantly infringe on other treatments such as chemotherapy and dialysis, more frequently than the nursing staff and physicians would suggest⁽²⁵⁾.

In Geneva, 53 patients with advanced cancer who formulated their ADLW have had their end-of-life preferences respected by caregivers. Most patients died in the same unit where they described their wishes, and their intentions were not excessively vague, resulting from in-depth discussions with caregivers⁽³⁰⁾. In Colombia, only 14% of patients, from a total of 513, had formalized their ADLW for the end of their life and their choices were related to the rejection of futile measures and therapeutic obstinacy⁽⁴⁰⁾.

Patients want for their family, friends and doctors to be honest and discuss the processes of the disease as well as the treatment options⁽⁵⁵⁾. Thus, about 75% of patients want for their doctors to initiate this discussion⁽²⁵⁾ despite the anxiety about the inability to predict, in advance, what they would want in a future situation^(25,28). Under another approach, in the US, patients with cardiac impairment wanted to make their end-of-life decisions by considering the opinions of family members instead of leaving the decisions to doctors and nurses. Before a serious illness and inability for decision-making, 47% of patients preferred to write their ADLW to guide decisions, 27% preferred to have a substitute named in their advance directive to make the decisions, 22% preferred their families to make decisions and only 4% would leave decisions to their doctors⁽¹⁹⁾.

However, one of the main perceived barriers to the completion of the ADLW, in a research with 18 cancer patients and four family members in the United Kingdom, was the realization that doctors do not introduce the topic and the discussion about the ADLW⁽²⁸⁾, which can result in unwanted interventions⁽¹⁶⁾. This highlights the need for health care professionals to be informed about the advanced directives, raising the awareness of the patient's signs. Several participants suggested the nurses as being the most suitable professionals to lead these discussions, being that their knowledge to answer questions and provide information, by way of the bond of trust that develops over time in nurse-patient relations⁽²⁸⁾.

In the USA, a research developed with 415 heart patients enrolled in outpatient rehabilitation centers indicated that only 15% of the patients had been involved in discussions with their doctors about advance directives and 9% had had discussions about life support interventions. Discussions about advance directives were initiated more often by patients (66%), followed by family members (29%) and then doctors (5%). Discussions on life-support care were most often initiated by members of the family (51%), followed by patients (43%) and then doctors (6%)⁽¹⁹⁾.

In Thailand, in a study with 152 subjects regarding the preferences of patients with terminal illnesses on the decisions in relation to end-of-life care and cardiorespiratory resuscitation (CPR), it was found that 57.2% of patients respected the authority of the doctors to make decisions about end-of-life care, 28.3% transferred their decisions to their family and only 14.5% opted for shared decision-making between

their relatives and doctors. However, regarding the need for a decision for CPR, when participants were unable to make that decision, 44.1% of individuals had expressed a wish that the family makes decisions together with the doctors, 33.6% passed the decision to the family and only 22.4% transferred their decisions to their doctors⁽³²⁾.

In a study with 4,396 patients, 6% of Italian patients, 5% of Spanish patients, 16% of Belgian patients and 29% of Dutch patients would appoint a substitute decision maker⁽⁴¹⁾. Another study that tried to verify the effectiveness of advance directives found that patients and their appointed decision makers were only willing to express their preferences through verbal discussion and not through the signing of a document⁽²⁹⁾.

Regarding (dis)advantages and reasons for the use of the ADLW, patients who completed the ADLW presented a lower depression and anxiety index⁽³⁰⁾. The motivations of the patients to complete the ADLW would be related to the increase in their autonomy, improved communication with caregivers, fear of treatment, not wanting to be considered a burden, making sure that their preferences will be respected, to not be revived, to use high doses of painkillers in case of untreatable pain, the introduction of artificial nutrition, hydration, antibiotics, in addition to blood transfusion, desire to be transferred to another hospital and for re-hospitalization⁽³⁰⁾.

The main reasons for not completing the ADLW relate to difficulties in anticipating their wishes and the rapid onset of delusion or worsening conditions⁽³⁰⁾. They also noted the difficulties in organizing an ADLW, specifying preferences or limitations for the life-support treatment, beyond language that can come across as being vague and inconsistent for use in its implementation⁽²⁰⁾. One of the main warnings against the use of advanced directives in the decision making process at the end of life is that people may not be able to understand what is meant by any treatment option without being properly informed⁽²⁵⁾. A study performed with 157 patients attended by a palliative care team in the Bronx, New York, found that 33% of the patients had orders to not be resuscitated; however, following illuminating and educational guidelines, that number increased to 83.4%⁽³⁶⁾.

In the US, soon after the emergence of the Patient Self-Determination Act (PSDA) a study of two groups with a total of 167 adult patients, in which the first group received a brochure with a description of information regarding the ADLW and the medical interventions that are considered extraordinary, if they were used for a terminal patient. The second group received a booklet and discussed the topic with the doctor. Before the completion of the study, none of the patients had completed a living will, but 44% reported that they had spoken to members of their family about the treatment issues. After the interventions, of the 83 patients who had had access to the booklet, 61% had discussed with their family about the health care that they would like receive, or to not receive, if they were to become terminally ill. In the intervention of the use of the booklet and discussions with the doctor, 70% were interested in discussing the living will, 23% showed disinterest and a little resistance, and 7% were completely resistant. The conclusion was that the use of the booklet and discussions with doctors proved itself to be an effective strategy⁽¹³⁾.

In Brazil, there is little research on patients' perspectives regarding the ADLW practice. However, a study of 110 patients found that knowledge of the term living will increased 0.13 points (0 to 10 reference points) between patients, increasing to 9.56 the intention of preparing the ADLW on having presented its meaning, with a lower tendency for developing the living will in patients from 21 to 30 years, when compared to other age groups⁽⁴⁶⁾. Regarding the implementation of the living will in Brazil, the average acceptance among patients was 9.56. Actually, what the ADLW brings to light is that the illness and even the death must not remain in the hands of the health care professionals alone, reducing the incapable patient oblivious to the decisions being taken in respect to the role of man about his life that can be extended from the time of his illness to his death⁽⁵⁴⁾.

The family facing the Advance Directives of Living Will

Often, the decisions at the end of life that involve family members are motivated by the perception of a lack of dignity, due to progressive deterioration, poorly controlled pain management, abandonment of the patient, therapeutic cruelty and the unnecessary use of measures that postpone death⁽⁴⁰⁾. In South Korea, in research made with 1,289 family caregivers it was identified that 92.9% approved the necessity for the implementation of the ADLW⁽⁴³⁾. In the US, a survey of 100 patients and their substitute decision makers found that the substitutes made correct predictions in approximately 66% of the cases, being relevant factors associated with the patient having had discussions with their family in regard to end-of-life issues; to have private insurance, beyond the level of education of the patient and the patient's substitute⁽¹⁷⁾.

On the other hand, there is evidence that the substitutes are often unaware of the patient's preferences⁽¹⁷⁾. In addition, relatives of the terminally ill experience emotional conflicts between their desires to act according to the values of their loved one, not wanting to feel responsible for their death, the urge to chase any chance of recovery and the need to preserve the family's well being⁽³⁸⁾. Thus, intervention strategies are proposed to aid the formulation of more accurate judgments by the substitutes, whereas health professionals can actively encourage patients to talk to their families about their wishes. The doctors should also have more frank discussions with family members and the terminally ill about the prognosis of the disease⁽¹⁷⁾.

In other situations, patients can express their wishes, but their family members disconsider them. Thus, it is emphasized that the coexistence of durable power of attorney and the living will in a single document, namely, the realization of an ADLW, increases the certainty that the wishes of the patient will be attended to, because the substitute may decide for the patient when the living will can be omitted, assisting the medical team when the family refuse the manifest of the will. Nevertheless, research with doctors in Brazil showed the binding aspect of the living will and the difficulties concerning the wishes of the patient, when the family is against these wishes⁽⁴⁷⁾.

In the US, coping strategies included the possibility of remembering previous discussions with a family, sharing decisions about belongings with family members, to delay or postpone the decision-making and about religious or spiritual

practices. Research with 30 people responsible for the patients demonstrated conflicts in trying to reconcile the individual emotional needs of the family members with those of the patients. It also suggested strategies for doctors to improve their decision making processes, including attending to the emotions of the substitutes, and helping in the making of decisions by the family. Increased attention to the negative experiences of those responsible for the patients intensified requests to improve the widespread support for families whilst in the ICU⁽³⁸⁾.

As such, it is essential and necessary that the wishes at the end-of-life care are recorded in writing, to prevent and resolve conflicts, especially when family members differ on the conduct to be taken, particularly in light of doubts by professionals who could act in the interests of the family and not in those of the patients.

The family plays an indispensable role in the context of end of life care, mainly due to the fact that, sometimes, it is them who take responsibility for the decisions for the limitation of therapeutic efforts. Thus, it is important to seek to keep the patient, if possible, and the patients family, informed about the situation and the evolution of the disease, whereas only with the interaction of multidisciplinary teams, patients and families, will it be possible to establish action throughout the patient's particular situation, exempting any sort of resentment or regret for some action having been performed or not⁽⁵⁶⁾. In this way, the inclusion of the ADLW, with the appointment of a representative who is able to answer for the terminally ill, is an alternative to allow for the patients' wishes to be respected by their families. Furthermore, the living will consists of a possibility to avoid or resolve ethical and bioethical issues between doctors and patient-families in extreme situations such as those resulting in the end of life⁽⁴⁴⁾.

It has been highlighted that in Brazil research has indicated that knowledge of the term "living will", by family members or companions, was 0.41 points on a scale of 0 to 10. After the explanation of the meanings, the intention of drawing up the living will obtained an average score of 9.39 among the companions. The average acceptance of the deployment of a living will in Brazil was 9.75 among the companions. The families also indicated that it is considered as being more appropriate when the decisions were taken by doctors (8.92) or by doctors along with patients (8.87), than when excluding their participation⁽⁴⁶⁾.

Thus, the needs of the terminally ill, so often isolated by society, increase the requirements when care is taken in the comfort that it promotes the physical, intellectual and emotional quality of life without disregarding familiar and other social aspects⁽⁵³⁾.

End-of-life situations relate to several actors: patients, family, health care teams and hospital staff, and should the parties be involved in making any decisions, the pros and cons of each option should be considered.

DISCUSSION

The ADLW is designed to conserve personal autonomy based on the belief that patients who lose their decision making abilities would be likely to receive the care that they chose and their absence in the process can lead to aggressive and unwanted care that is associated with a reduction in their quality

of life and care⁽⁴³⁾. In addition to this, it protects the doctors and the health care professionals in terms of accountability, whether in the context of their class entity, in a legal sense⁽¹⁰⁾ or whether they perform, or not, the treatments and care that had been previously chosen by the patient when the patient was considered able⁽⁶⁾. So, the preservation of the autonomy and the doctor-patient relationship are decisive factors for the applicability of ADLW^(10,30), representing a breakthrough in assisting the terminally ill by ensuring that nothing will be performed against their wishes^(28,53).

It becomes imperative that discussions about the ADLW occur effectively, carefully and scientifically⁽¹⁰⁾.

In the international arena, the increasing development of research is seen to bring a greater feasibility and acceptability^(24-25,36-37,43) from the advanced directives, although expressions of discomfort from the patients that adhere to this practice still occur due to a lack of knowledge. There is a trend that the terminally ill prefer to live life with quality than to have their suffering extended with heroic techniques that do not result in the healing of diseases^(17,25).

The most evident scientific literature is found in the US, as a result of the discussions on the subject that were started by the PSDA, a law applicable since 1991 that presented three ways to implement the advance directives: living will, durable power of attorney for health care and the advance medical care directive⁽³⁾. This encouraged and contributed to the discussions and legalization of the practice in other countries.

The scientific literature about the ADLW in Brazil is incipient with a lack of empirical research on the subject regarding assessment and practice to sustain and contribute to discussions related to the implementation of the ADLW. Unlike in the international scenario, which includes research with information concerning the effectiveness of the application of the ADLW, in the national scene, the studies lack research focusing on its applicability in the various contexts of health care and the population. However, what it does realize is that, although still insufficient, in 2013 there was an increase in publications possibly associated with the adoption of the Resolution of the Federal Council of Medicine on the ADLW, in 2012⁽⁷⁾. Studies have pointed towards a trend of acceptability, applicability and implementation of the ADLW⁽⁴⁶⁾, despite doubts that permeate this practice, demonstrating that health care professionals remain absent in this process due to the lack of clarification of the resolution that supports this practice and also due to the absence of Brazilian legislation on the subject.

For the ADLW, it is necessary for the assimilation of the status of the diagnosis and for the prognosis to be given to families and patients because research has shown difficulties in joining the practice of describing wishes, a result of poor professional communication with the interested parties, making it difficult to predict what might happen, or due to family members or substitutes not knowing how to act, mainly because of a lack of communication with patients about their wishes which in turn causes conflicts^(17,38,56).

Therefore, it is necessary for prior conversations for clarification to be combined with an educational process^(13,20,25,28,30). Family members that discuss, in an illuminating and honest

way with the patients about their prognosis and treatment options went on to later complete the ADLW^(30,46,55). It is worthwhile to highlight that the importance of the educational process, as well as the statements made by professionals, resulted in a higher completion rate of the ADLW by patients⁽¹³⁾.

The dependence of the limitation treatment decisions by representatives and family members of the terminally ill seems undeniable for the ADLW. In the international scope, some research indicate that family members and substitute decision makers play an indispensable role in view of decisions involving the end of life^(17,36,38,40,43) to ease the burdens of families concerning liability for the conduct of the treatments of the terminally ill, thus reducing the burdens caused by their decision making⁽²²⁾. Beyond this, bereaved family members indicated that by the conclusion of an advance directive they were less preoccupied as to the conduct to be carried out, increasing the use of palliative care⁽⁵⁷⁾.

Health care professionals have important influence in the assistance to patients, and can propose the ADLW practice, in a contextualized manner, through its interaction with families and patients. We point out that students and health care professionals (nurses and doctors) value the practice of completing the ADLW^(14,21,24,37,43,52). However, sometimes, they show a resistance for holding discussions on its implementation with patients and their families. In many instances, the expressed wishes are not met by the professionals, because of ethical conflicts that exist due to the accountability of their actions⁽¹⁸⁾.

Based on this assumption, choosing the correct time for discussion about the ADLW is susceptible to influence its acceptability and effect. The discussion can be initiated after the recurrence of a disease or when the treatment fails and the prognosis is poor. People that start discussions about the ADLW must be agile in their responses to signs of discomfort from the patient, and these discussions should preferably unfold over a certain number of meetings, conducted by a sufficiently trained professional who can speak knowledgeably and who has an ability to answer questions, adapting themselves to the individual and who can avoid the destruction of hope⁽²⁸⁾.

There is a great interest from health care professionals on the applicability of the ADLW, however, their actions appear masked by the deficiency in the present communication in the relationship of the doctors with the patients or families regarding the situation of the terminally ill, causing the ADLW to be filled out while not understanding the situation. Still, the compulsory routine and automatic inclusion of the subject with patients is not a viable alternative because it must be contextualized, discussed and argued, providing opportunities for the condition of the patients to express their wishes, because it must be treated as a personal decision, free from interference.

Nurses were recommended as the most suitable professionals to commence the discussions about ADLW, due to their proximity and to the relationship of trust that they have established with the patients and also for their knowledge to provide the information that may be required⁽²⁸⁾.

In addition to this, patients prefer that doctors begin the conversation about the ADLW^(25,28,32), however, surveys also point out that patients wish to make their own decisions, free from

external interference, or delegating to the family or doctor⁽¹⁹⁾, which may be made complicated by the lack of a written record.

FINAL CONSIDERATIONS

From the analysis of the national and international scientific publications about the ADLW as applied to the terminally ill, it was noted that this practice has made it possible for patients have their wishes met for the end of their lives and that those responsible for decisions involving limitations of treatment can guarantee meeting the wishes of the patient, reducing potential conflicts from indecision in how to act in a given situation. In addition, it ensures on behalf of the health care professionals a minimization of the dilemmas faced in situations involving the terminally ill and questions related to the end of life.

The analysis of the articles from this review allowed us to demonstrate the importance of the ADLW in the context of the assistance to the terminally ill, as well as the feasibility of its execution when contextualized in the patient-family-professional relationship, considering respect for personal autonomy and the maintenance of the patient's human dignity.

In Brazil, in addition to the need for further clarification regarding the provisions of the Resolution of the Federal Council of Medicine, which require an interpretation that is free from doubt for its implementation, the need emerges for research on the subject focusing more specifically on the applicability of the ADLW, in virtue of its practice being extremely incipient. In the international environment, this practice is effective, especially when performed with a multidisciplinary approach, with family participation and where patients' wishes are respected.

Health care professionals must be continuously committed to the idea that the personal autonomy of the patient is not

absent upon the loss of their ability to make decisions. It is necessary to respect the choices expressed whilst the patient is still able, or that the patient can abdicate the decisions to family members or guardians whom have knowledge of the patient, to assist in the conduct, whilst considering the wishes of the patient related to their autonomy and dignity.

The application of the ADLW can further bring greater support to nursing, during situations that will impose ethical dilemmas, especially when the preferred medical conduct is not made explicit, such as in the example of do-not-resuscitate order cases. Thus, matters relating to the terminally ill must be inserted in all contexts of education and health care to propose familiarization with the theme which at times is treated in a veiled way by health care professionals. Attention is needed to be paid to matters relating to the ADLW as an alternative paradigm shift, considered as a differentiated approach by the professionals of the population to stimulate the transformation of the dying experience into something to be lived and accepted.

As a strong point, this study shows an overview of the effects of the application of the ADLW on different continents and with different populations, to contribute to the reflections on the topic in the Brazilian scene.

However, considering the limitations of this review, in addition to the lack of assessment of the quality of the instrumental studies themselves and due to a limitation of language, it should be noted that the search did not include law journals, due to the emphasis on the ADLW to the terminally ill, as advocated in Brazil, from the Resolution of the Federal Council of Medicine. It is expected, however, to contribute with other research on the subject, considering the lack of previous reviews on the application of the ADLW.

REFERENCES

1. Moreira MS. Diretivas antecipadas de vontade: um estudo sobre a declaração prévia para o fim da vida. In: Dadalto L. *Diretivas antecipadas de vontade: ensaios sobre o direito à autodeterminação*. Belo Horizonte: Letramento; 2013.
2. Beauchamp TL, Childress JF. *Princípios da ética biomédica*. 4. ed. São Paulo: Loyola; 2002.
3. Alves CA. [Language, Advance Directives and Living Will: a national and international interface]. *Bioethikos* [Internet]. 2013 [cited 2014 Nov 03];7(3):259-70. Available from: <http://www.saocamilo-sp.br/pdf/bioethikos/105/1810.pdf> Portuguese.
4. Rajão RBD. Diretivas antecipadas de vontade e a eutanásia. In: Dadalto L. *Diretivas antecipadas de vontade: ensaios sobre o direito à autodeterminação*. Belo Horizonte: Letramento; 2013.
5. Dadalto L. [Distortion on living will in Brazil (or why it is necessary to talk about a prior declaration of will of terminal patient)]. *Rev Bioét Derecho* [Internet]. 2013 [cited 2014 Nov 03];28:61-71. Available from: <http://scielo.isciii.es/pdf/bioetica/n28/articulo5.pdf> Portuguese.
6. Bomtempo VT. [Advance directives: a tool that will ensure a die with dignity]. *Rev Bioét Derecho* [Internet]. 2012 [cited 2014 Nov 03];26:22-30. Available from: http://www.ub.edu/fildt/revista/pdf/rbyd26_art-vieira.pdf Portuguese.
7. Conselho Federal de Medicina (BR). Resolução nº. 1.995, de 9 de agosto de 2012. Dispõe sobre as diretivas antecipadas de vontade dos pacientes [Internet]. *Diário Oficial da União* 31 ago 2012 [cited 2013 Sep 05];Seção 1:269-70. Available from: http://www.portalmédico.org.br/resolucoes/CFM/2012/1995_2012.pdf
8. Dadalto L. [Legal repercussions of the Resolution CFM 1.995/12]. *Rev Bioét* [Internet]. 2013 [cited 2014 Nov 03];21(1):106-12. Available from: http://revistabioetica.cfm.org.br/index.php/revista_bioetica/article/view/791/861 Portuguese.
9. Bussinguer ECA, Barcellos IA. [The right to live one's own death and its constitutionality]. *Cien Saude Colet* [Internet]. 2013 [Internet]. 2013 [cited 2014 Nov 03];18(9):2691-98. Available from: <http://www.scielo.br/pdf/csc/v18n9/v18n9a24.pdf> Portuguese.

10. Dadalto L. Capacidade versus discernimento: quem pode fazer diretivas antecipadas de vontade? In: Dadalto L. *Dirretivas antecipadas de vontade: ensaios sobre o direito à autodeterminação*. Belo Horizonte: Letramento; 2013.
11. Menezes KDS, Silveira RCCP, Galvão CM. [Integrative literature review: a research method to incorporate evidence in health care and nursing]. *Texto & Contexto Enferm* [Internet]. 2008 Oct [cited 2014 Nov 03];17(4):758-64. Available from: http://www.scielo.br/readcube/epdf.php?doi=10.1590/S0104-07072008000400018&pid=S0104-07072008000400018&pdf_path=tce/v17n4/18.pdf&lang=pt Portuguese.
12. Bardin L. *Análise de conteúdo*. Lisboa: Edições 70; 2011.
13. Hare J, Nelson C. Will outpatients complete living wills? A comparison of two interventions. *J Gen Intern Med* [Internet]. 1991 [cited 2014 Nov 03];6(1):41-6. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/1999745>
14. Hughes DL, Singer PA. Family physicians' attitudes toward advance directives. *CMAJ* [Internet]. 1992 [cited 2014 Nov 02];146(11):1937-44. Available from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1490365/pdf/cmaj00300-0071.pdf>
15. Solomon MZ, Odonnell L, Jennings B, Guilfooy V, Wolf SM, Nolan K, et al. Decisions near the end of life: professional views on life-sustaining treatments. *Am J Public Health* [Internet]. 1993 Jan [updated 2015 May 28; cited 2014 Nov 02];83(1):14-23. Available from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1694502/pdf/amjph00525-0016.pdf>
16. Hofmann JC, Wenger NS, Davis RB, Teno J, Connors AF, Desbiens N, et al. Patient preferences for communication with physicians about end-of-life decisions. *Ann Intern Med* [Internet]. 1997 Jul [updated 2015 May 28; cited 2014 Nov 03];127(1):1-12. Available from: <http://annals.org/article.aspx?articleid=710642>
17. Sulmasy DP, Terry PB, Weisman CS, Miller DJ, Stallings RY, Vettese MA, et al. The accuracy of substituted judgments in patients with terminal diagnoses. *Ann Intern Med* [Internet]. 1998 Apr [updated 2015 May 28; cited 2014 Nov 02];128(8):621-9. Available from: <http://annals.org/article.aspx?articleid=711321>
18. Pierce SF. Allowing and assisting patients to die: the perspectives of oncology practitioners. *J Adv Nurs* [Internet]. 1999 Sep [updated 2015 May 28; cited 2014 Nov 02];30(3):616-22. Available from: <http://onlinelibrary.wiley.com/doi/10.1046/j.1365-2648.1999.01132.x/epdf>
19. John E, Heffner JE, Barbieri C. End-of-life care preferences of patients enrolled in cardiovascular rehabilitation programs. *Chest* [Internet]. 2000 May [updated 2015 May 28; cited 2014 Nov 02];117(5):1474-9. Available from: <http://journal.publications.chestnet.org/data/Journals/CHEST/21945/1474.pdf>
20. Happ MB, Capezuti E, Strumpf NE, Wagner L, Cunningham S, Evans L, et al. Advance care planning and end-of-life care for hospitalized nursing residents. *J Am Geriatr Soc* [Internet]. 2002 May [updated 2015 May 28; cited 2014 Nov 04];50(5):829-37. Available from: <http://onlinelibrary.wiley.com/doi/10.1046/j.1532-5415.2002.50207.x/pdf>
21. Masuda Y, Fetters MD, Hattori A, Mogi N, Naito M, Iguchi A, et al. Physicians's reports on the impact of living wills at the end of life in Japan. *J Med Ethics* [Internet]. 2003 [updated 2015 May 28; cited 2014 Nov 03];29(4):248-52. Available from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1733775/pdf/v029p00248.pdf>
22. Seymour J, Gott M, Bellamy G, Ahmedzai SH, Clark D. Planning for the end of life: the views of older people about advance care statements. *Soc Sci Med* [Internet]. 2004 Jul [updated 2015 May 28; cited 2014 Nov 03];59(1):57-68. Available from: <http://www.sciencedirect.com/science/article/pii/S0277953603005410>
23. Pasman HRW, The BAM, Onwuteaka-Philipsen BD, Ribbe MW, Van der Wal G. Participants in the decision making on artificial nutrition and hydration to demented nursing home patients: a qualitative study. *J Aging Stud* [Internet]. 2004 [cited 2014 Nov 03];18(3):321-35. Available from: <http://www.sciencedirect.com/science/article/pii/S0890406504000246>
24. Buss MK, Alexander GC, Switzer GE, Arnold RM. Assessing competence of residents to discuss end-of-life issues. *J Palliat Med* [Internet]. 2005 [cited 2014 Nov 03];8(2):363-71. Available from: <http://online.liebertpub.com/doi/abs/10.1089/jpm.2005.8.363>
25. Sahn S, Will R, Hommel G. What are cancer patients' preferences about treatment at the end of life, and who should start talking about it? A comparison with healthy people and medical staff. *Support Care Cancer* [Internet]. 2005 Apr [cited 2014 Nov 03];13(4):206-14. Available from: <http://link.springer.com/article/10.1007%2Fs00520-004-0725-z>
26. Ditto PH, Jacobson JA, Smucker WD, Danks JH, Fagerlin A. Context changes choices: a prospective study of the effects of hospitalization on life-sustaining treatment preferences. *Med Decis Making* [Internet]. 2006 Jul-Aug [cited 2014 Nov 03];26(4):313-22. Available from: <https://webfiles.uci.edu/phditto/peterditto/Publications/Ditto%20et%20al%202006%20MDM.pdf?uniq=-5wjp3y>
27. Van OB, Simon A. Importance of the advance directive and the beginning of the dying process from the point of view of German doctors and judges dealing with guardianship matters: results of an empirical survey. *J Med Ethics* [Internet]. 2006 Nov [cited 2014 Nov 04];32(11):623-6. Available from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2563284/pdf/623.pdf>
28. Barnes K, Jones L, Tookman A, King M. Acceptability of an advance care planning interview schedule: a focus group study. *Palliat Med* [Internet]. 2007 [cited 2014 Nov 04];21(1):23-8. Available from: <http://pmj.sagepub.com/content/21/1/23.long>
29. Sittisombut S, Maxwell C, Love E, Sitthi-amorn C. Effectiveness of advance directives for the care of terminally ill patients in Chiang Mai University Hospital, Thailand. *Nurs Health Sci* [Internet]. 2008 Mar [cited 2014 Nov 04];10(1):37-42. Available from: <http://onlinelibrary.wiley.com/doi/10.1111/j.1442-2018.2007.00371.x/epdf>
30. Pautex S, Herrmann FR, Zulian GB. Role of advance directives in palliative care units: a prospective study. *J Palliat Med* [Internet]. 2008 Oct [cited 2014 Nov 04];22(7):835-41. Available from: <http://pmj.sagepub.com/content/22/7/835.long>
31. Levin TT, Li Y, Weiner JS, Lewis F, Bartell A, Piercy J, et al. How do-not-resuscitate orders are utilized in cancer patients: timing relative to death and communication-training

- implications. *Palliat Support Care* [Internet]. 2008 Dec [cited 2014 Nov 04];6(4):341-8. Available from: <http://journals.cambridge.org/action/displayFulltext?type=1&id=2658880&jid=PAX&volumeld=6&issueld=04&aid=2658872&bodyId=&membershipNumber=&societyEtoCSession=>
32. Sittisombut S, Inthong S. Surrogate decision-maker for end-of-life care in terminally ill patients at Chiang Mai University Hospital, Thailand. *Int J Nurs Pract* [Internet]. 2009 [cited 2014 Nov 04];15(2):119-25. Available from: <http://onlinelibrary.wiley.com/doi/10.1111/j.1440-172X.2009.01730.x/epdf>
 33. Wilson E, Seymour JE, Perkins P. Working with the Mental Capacity Act: findings from specialist palliative and neurological care settings. *J Palliat Med* [Internet]. 2010 [cited 2015 Jan 01];24(4):396-402. Available from: <http://pmj.sagepub.com/content/24/4/396.long>
 34. Van Wijmen MPS, Rurup ML, Pasman HRW, Kaspers PJ, Onwuteaka-philipen BD. Design of the Advance Directives Cohort: a study of end-of-life decision-making focusing on Advance Directives. *BMC Public Health* [Internet]. 2010 [cited 2014 Nov 03];10:166. Available from: <http://www.biomedcentral.com/content/pdf/1471-2458-10-166.pdf>
 35. Hu WY, Huang CH, Chiu TY, Hung SH, Peng JK, Chen CY. Factors that influence the participation of healthcare professionals in advance care planning for patients with terminal cancer: a nationwide survey in Taiwan. *Soc Sci Med* [Internet]. 2010 [cited 2014 Nov 03];70(11):1701-4. Available from: <http://www.sciencedirect.com/science/article/pii/S027795361000170X>
 36. O'Mahony S, McHenry J, Blank AE, Snow D, Eti Karakas S, Santoro G, et al. Preliminary report of the integration of a palliative care team into an intensive care unit. *Palliat Med* [Internet]. 2010 [cited 2014 Nov 03];24(2):154-65. Available from: <http://pmj.sagepub.com/content/24/2/154.long>
 37. Franco TB, Silva, GZA, Saturno Hernández PJ. [Advanced knowledge of patient preferences for end-of-life care in national health service hospitals of the Murcia Region]. *Rev Calid Asist* [Internet]. 2011 May-Jun [cited 2014 Nov 03];26(3):152-60. Available from: <http://www.sciencedirect.com/science/article/pii/S1134282X11000273> Spanish.
 38. Schenker Y, Crowley-Matoka M, Dohan D, Tiver GA, Arnold RM, White DB. I don't want to be the one saying 'we should just let him die': intrapersonal tensions experienced by surrogate decision makers in the ICU. *J Gen Intern Med* [Internet]. 2012 Dec [cited 2014 Nov 03];27(12):1657-65. Available from: <http://link.springer.com/article/10.1007%2F11606-012-2129-y>
 39. Bryon E, Casterle BD, Gastmans C. Because we see them naked' - nurses' experiences in caring for hospitalized patients with dementia: considering artificial nutrition or hydration. *Bioethics* [Internet]. 2012 Jul [cited 2014 Nov 03];26(6):285-95. Available from: <http://onlinelibrary.wiley.com/doi/10.1111/j.1467-8519.2010.01875.x/epdf>
 40. Sarmiento-Medina MI, Vargas-Cruz SL, Velásquez-Jiménez CM, Jaramillo MS. [Terminally-ill patients' end of life problems and related decisions]. *Rev Salud Public* [Internet]. 2012 Jan-Feb [cited 2014 Nov 03];14(1):116-28. Available from: <http://www.scielosp.org/pdf/rsap/v14n1/v14n1a10.pdf> Spanish.
 41. Evans N, Pasman HR, Vega Alonso T, Van den Block L, Miccinesi G, Van Casteren V, et al. End-of-life decisions: a cross-national study of treatment preference discussions and surrogate decision-maker appointments. *Plos One* [Internet]. 2013 [cited 2014 Nov 05];8(3):e57965. Available from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3589464/pdf/pone.0057965.pdf>
 42. Cucalón-Arenal JM, Marín-Ibáñez A, Cía-Gómez P, Blay-Cortés MG. [University students' opinions regarding end-of-life care]. *FEM* [Internet]. 2013 [cited 2014 Nov 05];16(3):181-6. Available from: <http://scielo.isciii.es/pdf/fem/v16n3/original7.pdf> Spanish.
 43. Keam B, Yun YH, Heo DS, Park BW, Cho CH, Kim S, et al. The attitudes of Korean cancer patients, family caregivers, oncologists, and members of the general public toward advance directives. *Support Care Cancer* [Internet]. 2013 May [cited 2014 Nov 05];21(5):1437-44. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/23262809>
 44. Piccini CF, Steffani JA, Bonamigo EL, Bortoluzzi MC, Schlemper Jr BR. Testamento Vital na perspectiva de médicos, advogados e estudantes. *Bioethikos* [Internet]. 2011 [cited 2014 Nov 05];5(4):384-91. Available from: <http://www.saocamilo-sp.br/pdf/bioethikos/89/A4.pdf>
 45. Stolz C, Gehlen G, Bonamigo EL, Bortoluzzi MC. Manifestação das vontades antecipadas do paciente como fator inibidor da distanásia. *Rev Bioét* [Internet]. 2011 [updated 28 maio 2015; cited 04 nov 2014];19(3):833-45. Available from: http://revistabioetica.cfm.org.br/index.php/revista_bioetica/article/viewArticle/679
 46. Campos MO, Bonamigo EL, Steffani JA, Piccini CF, Caron R. [Living wills: perception of oncology patients and accompanying family members]. *Bioethikos* [Internet]. 2012 [cited 2014 Nov 05];6(3):253-9. Available from: <http://www.saocamilo-sp.br/pdf/bioethikos/96/1.pdf> Portuguese.
 47. Dadalto L, Tupinambás U, Greco DB. [Advanced directive: a brasilian model]. *Rev Bioét* [Internet]. 2013 [cited 2014 Nov 05];21(3):463-76. Available from: <http://www.scielo.br/pdf/bioet/v21n3/a11v21n3.pdf> Portuguese.
 48. Rocha AR, Buonicore GP, Silva AC, Pithan LH, Feijó AGS. [Prior declaration of will of the terminal patient: bioethical reflection]. *Rev Bioét* [Internet]. 2013 [cited 2014 Nov 05];21(1): 84-95. Available from: http://revistabioetica.cfm.org.br/index.php/revista_bioetica/article/viewFile/790/859 Portuguese.
 49. Alves CA, Fernandes MS, Goldim JR. [Advance directives: a new challenge to the doctor-patient relationship]. *Rev HCPA* [Internet]. 2012 [cited 2014 Nov 05];32(3):358-62. Available from: <http://seer.ufrgs.br/index.php/hcpa/article/view/33981/22041> Portuguese.
 50. Dadaldo L. Declaração prévia de vontade do paciente terminal. *Rev Bioét* [Internet]. 2009 [cited 2014 Nov 04];17(3):523-43. Available from: http://www.revistabioetica.cfm.org.br/index.php/revista_bioetica/article/viewFile/515/516
 51. Ribeiro DC. [Autonomy: to live one's own life and to die one's own death]. *Cad Saude Publica* [Internet]. 2006 [cited 2014 Nov 05];22(8):17-49. Available from: <http://www.scielo.br/pdf/csp/v22n8/24.pdf> Portuguese.
 52. Simón-Lorsa P, Tamayo-Velázquez MI, Barrio-Cantalejo IM. Advance directives in Spain. Perspectives from a medical

- bioethicist approach. *Bioethics* [Internet]. 2008 Jul [cited 2014 Nov 05];22(6):346-54. Available from: <http://onlinelibrary.wiley.com/doi/10.1111/j.1467-8519.2008.00644.x/epdf>
53. Neves MEO. Percepção dos Enfermeiros sobre Diretivas Antecipadas de Vontade [dissertação]. Viseu: Escola Superior de Saúde de Viseu; 2013. 135p.
54. Holland S. Bioética enfoque filosófico. São Paulo: Loyola; 2008.
55. Kuhl D, Stanbrook MB, Hébert PC. What people want at the end of life [editorial]. *CMAJ* [Internet]. 2010 [cited 2014 Nov 04];182(16):1707. Available from: http://pa.lliaticare.yale.edu/student/361_166138_Whatpeoplewantattheendoflife.pdf
56. Cogo SB. Representação social da ortotanásia: significados atribuídos por enfermeiros e médicos na Unidade de Terapia Intensiva. [dissertação]. Santa Maria: Universidade Federal de Santa Maria; 2008. 182p.
57. Rondeau DF, Schmidt TA. Treating cancer patients who are near the end of life in the emergency department. *Emerg Med Clin North Am* [Internet]. 2009 [cited 2014 Nov 04];27(2):341-54. Available from: <http://www.sciencedirect.com/science/article/pii/S0733862709000194>
-