

Living will: What do healthcare professionals think about it?

José Antonio Chehuen Neto ¹, Renato Erothildes Ferreira ², Natália Cristina Simão Da Silva ³, Álvaro Henrique De Almeida Delgado ⁴, Caio Gomes Tabet ⁵, Guilherme Gomide Almeida ⁶, Isadora Figueiredo Vieira ⁷

Abstract

The living will is a document in which the patients specify their wishes regarding what treatments should be carried out if they are in terminal condition. As it is a new subject, it has been generating doubts in relation to its diffusion, social acceptance and ethical principles. Our study is aimed at verifying the knowledge of healthcare professionals about this document, and analyzing different aspects related to its legal regulation and applicability. A cross-sectional, descriptive and quantitative study was performed in a sample of 351 healthcare professionals, through the application of a survey containing 29 multiple-choice questions, 9 about the sociodemographic profile and 20 about the opinion of the interviewees regarding the document. Among the respondents, 7.98% declared they knew how to write the document, 73.79% felt safer with its regulation, and 61.82% would do it for themselves ($p < 0.05$). Despite not previously knowing what a living will was, the majority of the sample stated they were in favour of the document and its regulation. This result suggests a need for further discussion and disclosure on the subject in the health sector.

Keywords: Advance directives. Bioethics. Critical illness. Professional practice.

Resumo

Testamento vital: o que pensam profissionais de saúde?

O testamento vital é um documento em que os pacientes expõem suas vontades acerca de quais tratamentos serão realizados caso se encontrem em estado terminal. Por ser tema recente, tem gerado dúvidas em relação à sua difusão, aceitação social e princípios éticos. Nosso objetivo foi verificar o grau de conhecimento dos profissionais de saúde a respeito desse documento e analisar aspectos de sua regulamentação legal e aplicabilidade. Tratou-se de pesquisa transversal, descritiva e quantitativa, com 351 profissionais de saúde, mediante entrevista composta de 29 questões de múltipla escolha, 9 abrangendo o perfil sociodemográfico da amostra e 20, a opinião sobre o testamento vital. Entre os entrevistados, 7,98% declararam saber redigi-lo, 73,79% se sentiriam mais seguros com sua regulamentação e 61,82% o fariam para si próprios ($p < 0,05$). A maioria amostral declarou-se favorável ao documento e à sua regulamentação, apesar de desconhecê-lo previamente, o que sugere a necessidade de maior discussão e divulgação sobre o tema na área de saúde.

Palavras-chave: Bioética. Diretivas antecipadas. Estado terminal. Prática profissional.

Resumen

Testamento vital: ¿lo que piensan profesionales de la salud?

El testamento vital es un documento en el cual los pacientes exponen sus deseos acerca de qué tratamientos se realizarán si se encuentran en estado terminal. Por ser un tema reciente, ha generado dudas sobre su difusión, aceptación social y principios éticos. Nuestro objetivo consiste en verificar el grado de conocimiento de los profesionales de la salud sobre este documento y analizar aspectos de su regulación legal y aplicabilidad. Se trata de una investigación transversal, descriptiva y cuantitativa, con 351 profesionales de la salud, a través de una entrevista que consta de 29 preguntas de opción múltiple, 9 relativas al perfil sociodemográfico de la muestra y 20 a la opinión sobre el testamento vital. Un 7,98% afirmaron saber redactarlo. Un 73,79% demostraron más seguridad con respecto a su regulación y un 61,82% lo harían para ellos mismos ($p < 0,05$). La mayoría de la muestra resultó favorable al documento y a su regulación, aunque lo desconocía anteriormente, lo que sugiere la necesidad de continuar el debate y la divulgación sobre el tema en el área de la salud.

Palabras-clave: Bioética. Directivas anticipadas. Enfermedad crítica. Práctica profesional.

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1. **Doutor** chehuen.neto@yahoo.com.br 2. **Mestre** renato.eferreira@gmail.com 3. **Graduanda** natcssilva@yahoo.com.br 4. **Graduando** alvaro.delgado87@gmail.com 5. **Graduando** caiotabet@hotmail.com 6. **Graduando** guiaffs@yahoo.com.br 7. **Graduanda** isa.dora_94@hotmail.com – Faculdade de Medicina da Universidade Federal de Juiz de Fora, Juiz de Fora/MG, Brasil.

Correspondência

José Antonio Chehuen Neto – Av. Presidente Itamar Franco, 1.495/1001, Centro CEP 36016-320. Juiz de Fora/MG, Brasil.

Declaram não haver conflito de interesse.

The advance directives of a living will can be defined as written instructions in which the person, in a free and informed way, expresses their directives and preferences, in order to guide future decisions about their health. Living wills take effect from the time when there is medical proof that the patient is unable to make decisions and can be written by all adults, regardless of their current state of health. There are two types of advance directives: the power of attorney and the living will. The power of attorney corresponds to the appointment by the person of someone they trust to make decisions about the care of their health, if they ever become incapacitated. The living will is a legal authorisation, in which the patient defines what kind of treatment and medical procedure they want to undergo when a reversal of their clinical condition is no longer possible and they are not able to make decisions¹⁻⁴. Considering that this study focuses on the perspective of the health team, who are directly responsible for patient care, we chose to focus on the living will.

Lately, patients are taking a more active participatory and influential role in matters involving their own health, even in the most critical and conflicting matters - as in the case of terminal diseases⁵ - which contributes to increase the complexity of the patient's relationship with the health team. This behavioral change has arisen due to greater dissemination of technical and legal knowledge by the media, such as print, radio and television networks, as well as the internet. Health professionals have also adopted a new attitude in recent years, influenced by changes in the curriculum of medical schools, which seek to make more room for patient participation in decisions about treatment, stimulated largely by bioethics^{6,7}.

Some situations present conflicts arising from the change in the doctor-patient relationship. An example of this is a matter related to the right to life, where there is no certainty as to the cost-benefit of prolonging life if the application of technologies means only prolonging the patient's suffering. Another aspect likely to lead to conflict concerns the autonomy of the patient, is when the patient's views on key decisions to be made regarding their treatment differs from the opinion of relatives or attending professionals. Faced with such circumstances, the living will provides an option that is able to protect the patient's rights and endorse the attitudes of professionals in special situations⁸.

Some authors believe that the regulation of living wills would be a way to encourage euthanasia. In contrast, other scholars argue that its adoption does

not mean advocating the abbreviation of life nor the suspension of ordinary and palliative treatments, but the suspension of those extraordinary and futile procedures that fail to bring any obvious benefits to the patient^{4,9}. By following the determinations of the living will, the doctor would be respecting the bioethical principle of respect for autonomy, given that the document asserts the patient's right to consciously decide about the treatments to which they want to undergo or not, even if their choice goes against the opinion of the physician^{5,10,11}. To respect autonomy implies recognizing that the individual must decide and take action according to their own life plan, beliefs, aspirations and values, even when contrary to those prevailing in society¹².

Such questions have been raised recently with the publication of Resolution 1995/2012 by the Conselho Federal de Medicina (Brazilian Federal Council of Medicine - CFM), which recognizes the validity of advance directives of a living will and which protects the doctor to follow its provisions⁷. Although this decision has normative force, which means that the failure of planned actions goes against the Code of Medical Ethics (CEM), the resolution is not yet regulated in the Civil Code¹³. The absence of a definitive positioning in the legislative field can increase the insecurity of professionals to follow the decisions of a patient^{14,15}. Research that attempted to identify the attitude of professionals regarding the living showed that only 60.77% of respondents said they followed the decisions of patients¹⁶.

Another ethical question related to the living will is regarding the authenticity and impermanence of the decision of the patient, since the preparation of the document is based on an imaginary construction of how their life would be in some future situation never before experienced, and that, from the moment when they really experience such a condition, their point of view could change. Also, another conflicting factor is the ambiguity of the term "terminal patient", which is often linked to living wills, and currently the target of criticism. In this case, the word "terminal", which can cover different situations, is rather vague, which is the reason why it could interfere with the understanding and precision of those who produce the document¹⁷.

Given the importance of discussing the topic in Brazil, as about 40% of the country's hospital beds are occupied by terminal patients, there is little published research that assesses the level of knowledge about the living will (its definition and applicability) among patients and health professionals¹⁸. Investigations into the different positions and

views of those involved will always ensure a better understanding of the impacts of this document and will eventually assist in the decision-making by the authorities regarding its promotion and regulation.

Our study deals with an important issue regarding the Brazilian bioethical context, in which health professionals' understanding of the matter represents the possibility of knowing the underlying ethical challenges for professional practices in light of the living will. Thus, the research focused on the evaluation of multidisciplinary health teams, which are in constant contact with hospital patients. We aim, therefore, to verify the degree of knowledge these professionals have regarding the document, according to the different variables analyzed, and to identify aspects related both to its regulation, in the form of laws and resolutions, and to its application in the hospital.

Method

The research was cross-sectional, diligent, original, descriptive and quantitative, in which factor and outcomes were measured concurrently, with an estimate of the prevalence of the outcome variable, in this case, *the opinion of health professionals in the city of Juiz de Fora, Brazil, regarding the living will*¹⁹.

Participants were interviewed in their workplace, such as offices and clinics, across the whole city center, and randomly incorporated into the study. When the researcher did not find a qualified person in the sector to conduct an interview, new appointments were scheduled at different times. Juiz de Fora is characterized by a heavy centralization of health care facilities while the homes of the professionals are located in different regions (central, north, south, east, west) and city neighborhoods.

Inclusion criteria were: to be a health care professional in the fields of medicine, nursing, nutrition, psychology and physiotherapy; working in a hospital environment, because these professionals are more likely to deal with patients in severe and delicate clinical situations. As a sample loss, we defined the questionnaires interrupted for any reason, or with incomplete data, and failure to return the "termo de consentimento livre e esclarecido" (TCLE - informed consent form) signed.

The sample size calculated to research this health outcome was 351 individuals. This sample

spectrum strictly meets the criteria and statistical requirements and it took into account a sampling error of 4.5% (plus or minus). The data collection instrument consisted of a questionnaire composed of 29 questions, of which 9 were multiple choice on the socio-demographic profile of the sample, and 20 related to knowledge and opinion about the studied context (see Appendix).

The contextual variables of respondents were divided into groups and presented as follows: profession (medical doctor and other health professionals); stratified age (up to 35 years or over 35 years); sex (male or female); color (white or non-white); income (up to double the minimum wage or more than double the minimum wage); religious beliefs; training (technical course or degree); marital status (single or otherwise); living arrangements (living alone or other arrangement); place of residence. The study considered the following settings for methodological refinement:

- *Terminal patient*: one whose condition is irreversible, whether treated or not, and that is highly likely to die in a relatively short period of time²⁰;
- Unidade de Tratamento Intensivo (*Intensive Care Unit - UTI*): Hospital sector which provides intensive, continuous care to patients in critical condition;
- *Euthanasia*: precipitation of the death of an incurable patient, who is usually terminal and in great pain, motivated by compassion for the patient²¹;
- *Dysthanasia*: postponement of the dying process by obdurate therapy and the overuse of drugs and devices²¹;
- *Orthothanasia*: encouragement of the use of palliative care to relieve the patient's suffering, giving up mechanisms that are meant to prolong the process of dying, in an artificial and disproportionate manner, and accepting, therefore, the condition of human death²¹.

The professionals were addressed in a standardized manner by a trained researcher, who gave them detailed knowledge of the study, after which respondents were invited to participate in the study, voluntarily indicating their acceptance by signing the informed consent form. Training for the fieldwork was done through a pilot study with 12 subjects, and focused on identifying problems in understanding the questions, in order to ensure the quality of data collection and to get more cooperation from interviewees.

The research does not present immediate benefits to its participants; however, it allows the

identification of the perceptions and expectations of the sample related to living wills. The data collected can be a source of information regarding the subject, which will assist in the regulation of the document, by including the perspective of health professionals. Furthermore, it will enable discussion of possible criticism and questions, considering the complexity and differences of opinion surrounding the issue. Therefore, by undertaking such a debate, the whole of society will benefit indirectly.

Participation in the survey implied minimal risk to participants, that is, there was no interference from the researcher in any aspect of the respondents' physical, psychological and social well-being, as well as their privacy, as established by Resolution 466/2012 of the National Council of Health/Ministry of Health²², which regulates research involving human subjects. The interviews were conducted individually, and the participants' identities were kept confidential with no identification in any publication. The respondents incurred no cost nor received any financial benefit, and any questions they had, regarding any aspect of the study, were clarified. The respondents were free to participate or refuse to do so, given that they could provide or withdraw their consent or discontinue participation at any time. Therefore, their participation was voluntary, and the survey results remain at their disposal.

Statistical analysis

The variables analyzed were divided into two groups: 1) continuous quantitative (only for age), and 2) dichotomous qualitative. A descriptive and exploratory data analysis used absolute frequencies (n), relative frequencies (%), measures of central tendency (average), dispersion measurements (standard deviation) and a median, which was used as the cutoff point for age.

For the comparative analysis of the proportions of dichotomous variables (association between these variables), we applied the chi-squared test of independence (uncorrected). The significance level for this test was 5% ($p \leq 0.05$) for a 95% confidence interval.

For a dependent variable that takes only two values, as in our research, crosstabs was the analytical strategy chosen to estimate the risk of failure associated with several variables being considered. As is usual in such cases, we presented the results based on the estimation of the relative risk (RR) by the odds ratio (OR) calculation, thereby indicat-

ing how the probability of an event changes when it moves between different categories of the same variable. For the statistical processing and assembly of the database, the statistical software SPSS version 15.0, 2010 was used.

Results

With regard to the variable "profession", 41.9% of the sample consisted of medical doctors, and 58.1% of other health professionals. The average age was 36.6 ± 11.6 years and the median 35 years. The percentage of female respondents was 63.5% and males 36.5%. In the category "color", the self-declared "white" sample was the majority, with 78.9%, across all the areas surveyed, relative to 21.1% non-white (mixed-race, black, yellow and indigenous).

The social status of respondents was based on their income. The cutoff was equivalent to double the Brazilian minimum wage, and the results showed that 15.1% earn up to double the minimum wage and 84.9% earn more than double the minimum wage.

Regarding the location of the respondents' homes, it was found that 39.9% of them reside in the central area of the city, while 60.1% have their homes distributed throughout the northern, southern, eastern and western regions, and the rural areas.

With regard to the training of these professionals, the results revealed that 20.2% have technical qualifications and 79.8% have degrees.

Among the religious beliefs of the participants, Catholicism stood out, with 62.1%, while the Spiritualists totaled 16.8%, followed by evangelicals with 11.4%, and other beliefs (atheists and others) with 9.9%. The cutoff point was established between Catholics and non-Catholics: with 62.1% and 37.9%, respectively.

In the professional environment, 64.6% of medical doctors surveyed reported working in UTIs; while, among other health professionals this value was 50%, demonstrating that the majority of the sample works in this sector (OR = 182%).

With regard to the health professional's obligation to inform the patient about the living will, 79.6% of medical doctors and 68.1% of other health professionals agreed with this statement, showing that the majority is in favor of providing this type of information (OR = 182%). When asked whether pa-

tients often express opinions relating to therapeutic treatment that they will be submitted to, 81% of doctors and 70.1% of other health professionals said yes (OR = 181%).

Analyzing the frequency with which respondents deal with critically ill patients, 25.9% of doctors reported that they seldom deal with this type of patient. In the group of other health professionals the figure is 35.8% (OR = 62%).

When asked about the concept of euthanasia, most medical doctors (74.8%) claimed to know about it, as did 55.9% of other professionals, (OR = 234%).

Most respondents said they knew about the concept of orthothanasia, among them, 96.3% of doctors and only 40.7% of other health professionals (OR = 341%). The research reveal that 58.9% of the professionals who work in the UTI and 45.5% of those who do not work in this environment said they knew the term "orthothanasia" (OR = 172%).

Regarding the concept of dysthanasia, 58.5% of the doctors knew it, whereas, among other health professionals, this percentage was 37.2% (OR = 237%). Regarding the fact whether professionals feel at ease or do not feel at ease following the provisions contained in a living will, most participants indicated not being comfortable. When considering professional groups, 47.6% of medical doctors and 27.9% of other health professionals said that they felt free to follow the provisions (OR = 234%). As for the division of the groups in relation to the workplace, 41.6% of

those who work in the UTI and 29.2% of those not working in this environment declared they felt at ease with such conduct (OR = 172%).

When asked about the creation of a law to regulate the living will, most claimed to be in favor. Among occupational groups, 89.1% of medical doctors and 77.9% of other health professionals supported this proposal (OR = 238%). As for feeling safe with the regulations of this document, a large portion of the sample (73.8%) answered in the affirmative. Regarding the groups, 83% of doctors and 67.1% of other health professionals reported that they would feel more secure if there were regulations (OR = 238%).

When asked if they would make a living will for themselves, the majority of respondents said yes. In professional groups, 70.8% of medical doctors and 55.4% of other health professionals shared this opinion (OR = 195%). Meanwhile, when it comes to working in UTI, 67.5% of those who work and 54.6% of those who do not work in this environment said they would (OR = 173%). Regarding knowledge of CFM Resolution 1995/2012, 82.1% of the sample responded negatively. Those who said they know it represent 21.8% of those working in UTI and only 13% of those who do not work in UTI (OR = 187%). Although we have not observed statistically significant differences between groups in this respect, knowledge of the sample regarding the definition of the living will was generally low, with only 37.89% having said they knew it.

Table 1 - Medical doctors vs. Other health professionals

| Questions | Doctors | | Non-doctors | | Sig. | OR | IC 95% |
|---|---------|------|-------------|------|-------|--------|-----------|
| | n | % | n | % | | | |
| Works in UTI | 95 | 64,6 | 102 | 50 | 0,006 | 1,82 ↑ | 1,18-2,82 |
| Does not work in UTI | 52 | 35,4 | 102 | 50 | | | |
| The health professional should inform the patient about the living will | 117 | 79,6 | 139 | 68,1 | 0,017 | 1,82 ↑ | 1,10-3,00 |
| The health professional should not inform the patient about the living will | 30 | 20,4 | 65 | 31,9 | | | |
| Patients usually express their opinion | 119 | 81 | 143 | 70,1 | 0,021 | 1,81 ↑ | 1,09-3,01 |
| Patients usually do not express their opinion | 28 | 19 | 61 | 29,9 | | | |
| Seldom deal with severely ill patients | 38 | 25,9 | 73 | 35,8 | 0,048 | 0,62 ↑ | 0,39-0,99 |
| Often deal with severely ill patients | 109 | 74,1 | 131 | 64,2 | | | |
| Feel at ease following the determinations of a living will | 70 | 47,6 | 57 | 27,9 | 0,000 | 2,34 ↑ | 1,50-3,66 |
| Do not feel at ease following the determinations of a living will | 77 | 52,4 | 147 | 72,1 | | | |

(continua)

(conclusão)

| Questions | Doctors | | Non-doctors | | Sig. | OR | IC 95% |
|---|---------|------|-------------|------|-------|-------|-----------|
| | n | % | n | % | | | |
| In favor of the creation of regulatory law regarding living wills | 131 | 89,1 | 159 | 77,9 | 0,006 | 2,31↑ | 1,25-4,28 |
| Not in favor of the creation of regulatory law regarding living wills | 16 | 10,9 | 45 | 22,1 | | | |
| Would feel safer with the regulation of living wills | 122 | 83 | 137 | 67,1 | 0,001 | 2,38↑ | 1,41-4,01 |
| Would not feel safer with the regulation of living wills | 25 | 17 | 67 | 32,9 | | | |
| Would make a living will | 104 | 70,8 | 113 | 55,4 | 0,003 | 1,95↑ | 1,24-3,05 |
| Would not make a living will | 43 | 29,2 | 91 | 44,6 | | | |

Note 1. The figures in the columns represent the total sample (100%) in each category. Note 2. OR (odds ratio): values different from (1) were converted into percentage. If ↑, it is a risk factor; if ↓, it is a protective factor. Note 3. Sig. (statistical significance of differences): Pearson X² test.

Table 2 - Professionals working in UTI vs. Professionals who do not work in UTI

| Questions | Works in UTI | | Does not work in UTI | | Sig. | OR | IC 95% |
|---|--------------|------|----------------------|------|-------|-------|-----------|
| | n | % | n | % | | | |
| Seldom deal with severely ill patients | 38 | 19,3 | 73 | 47,4 | 0,000 | 0,26↑ | 0,16-0,42 |
| Often deal with severely ill patients | 159 | 80,7 | 81 | 52,6 | | | |
| Has acquaintances with terminal disease | 45 | 22,8 | 13 | 8,4 | 0,000 | 3,21↑ | 1,66-6,20 |
| Does not have acquaintances with terminal disease | 152 | 77,2 | 141 | 91,6 | | | |
| Feel at ease following the determinations of a living will | 82 | 41,6 | 45 | 29,2 | 0,016 | 1,72↑ | 1,10-2,70 |
| Do not feel at ease following the determinations of a living will | 115 | 58,4 | 109 | 70,8 | | | |
| Knows the Resolution CFM 1.995/2012 | 43 | 21,8 | 20 | 13 | 0,032 | 1,87↑ | 1,04-3,33 |
| Does not know the Resolution CFM 1.995/2012 | 154 | 78,2 | 134 | 87 | | | |
| Would make a living will | 133 | 67,5 | 84 | 54,6 | 0,013 | 1,73↑ | 1,12-2,67 |
| Would not make a living will | 64 | 32,5 | 70 | 45,4 | | | |

Note 1. The figures in the columns represent the total sample (100%) in each category. Note 2. OR (odds ratio): values different from (1) were converted into percentage. If ↑, it is a risk factor; if ↓, it is a protective factor. Note 3. Sig. (statistical significance of differences): Pearson X² test.

Discussion

Studies regarding the living will in Brazil are still very recent and scarce, especially when the focus is on the practice of health professionals. Therefore, it is expected that these professionals have scant knowledge of living wills, as shown in this study - where only 37.89% of respondents stated that they knew about the document - as well as in the specific literature¹⁶. This probably occurs be-

cause of the topicality of the subject, and the fact that the assessments of living wills are still basic and often restricted to the academic environment. Such questions highlight the need to broaden the debate and research on the topic, especially considering the changing panorama of the relationship between health staff and terminally ill patients²³.

Nowadays, patients bring ethical questions about the real value of therapies that seek to stave off death without, however, promoting quality of

life. Professionals who have more experience of patients' suffering and have sensitized themselves to the wishes expressed by their patients, are opposed to such unnecessary treatment. In our study, those who work in UTI and deal constantly with seriously ill patients were more inclined to follow the advance directives than those who work outside of this environment (Table 2). This fact is corroborated by the literature, which shows that the perception of health professionals regarding the situation of patients varies according to their work environment^{8,24,25}. Another significant aspect that reaffirms this finding, in the present study, is that the UTI professionals are also more inclined to draw up a living will for themselves (Table 2).

When it comes to team communication with the patient, the question arises whether to inform the patient or not about the living will. As evidenced by Antolín et al.²⁶, whose study examined whether the patients felt well informed or not, the vast majority of them reported not being sufficiently informed by the professionals. However, when we look at the other side of the relationship, most of our sample (Table 1) considered it their duty to inform the patient of the existence of the living will after becoming aware of it. This difference in perspective reinforces the need to improve the doctor-patient relationship and the dissemination of information regarding the topic.

Another relevant issue is the participation of patients in decisions about the therapeutic procedure that they will be submitted to. Until recently, this dialogue was not common; today, however, we can see a change in this outlook, reflected in patients' greater interest in their own treatment. In our research, most professionals said patients often express their opinion (Table 1). It is necessary, however, that the health team is also willing to discuss and try to adapt their approach in order to create greater trust and provide more effective palliative care. According to Jones et al.²⁷, patients over the age of 65, who require palliative care or are hospitalized in long-term institutions, tend to participate in decisions about their treatment, precisely because of their closer contact with the team that provides them care.

Although we have identified increased attention from the multidisciplinary team regarding the preferences of patients, there is still some concern regarding advance directives. In this study, most of the sample declared themselves uncomfortable following the determinations of a living will (Tables 1 and 2). This possibly happened because discussions

are still rudimentary and unable to answer questions regarding the approach to be adopted when the family does not agree with the determinations of the patient and regarding the ethical and legal implications that can affect the health care professional. In the research from Piccini et al.¹⁶, the majority of medical doctors in favor of the living will consider it useful, but limited. Probably this fact is associated with motives similar to those verified by our research.

The document is already part of the legal framework in several countries²⁸⁻³³; but in Brazil, professionals are guided solely by CFM Resolution 1995/2012, which recognizes the patient's wishes expressed in living wills and have normative force, by ensuring that the doctor is administratively linked to the patient's directives, and must therefore follow the patient's determinations. The CFM Resolution itself can and must have legal backing, since, with the advent of neo-constitutionalism, everything regarding fundamental rights dispenses with legal regulations to be effective¹⁴. Despite this, our study demonstrated that most professionals are unaware of such a resolution (Table 2), and, apparently, its applicability in patients' daily lives is low.

Despite the lack of mandatory inclusion of advance directives of will in the current legal framework, the presence of a specific law in the national legal framework would be important to enhance the existing efficiency, since such a law would supposedly give more security to doctors, patients and families regarding this delicate subject¹⁴. This fact is confirmed by our research, which finds that the majority of respondents reported that they would feel more secure with the regulation of living wills (Table 1).

Final considerations

The majority of health professionals interviewed were unaware of the living will and CFM Resolution 1995/2012. However, they support the creation of a specific law, since the regulation would facilitate the applicability of the document, providing more comfort and security to patients. Professionals working in the UTI, or who have extensive experience in dealing with serious illnesses, are more inclined to follow the determinations of the living will as well as prepare it for themselves.

Finally, although it is a widely accepted document among health professionals, the living will faces a major obstacle in its application: the fact that it is little known by the professionals themselves.

The data found in this study, combined with the large number of ethical issues involved, calls attention to the importance of broadening the discussion about this subject among health professionals. This

would contribute not only to the further spread of knowledge about CFM Resolution 1995/2012 but also to the formation of a more uniform approach for the needs of the terminally ill.

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Participation of the authors

Alvaro Henrique de Almeida Delgado, Caio Gomes Tabet, Guilherme Gomide Almeida, Isadora Figueiredo Vieira and Natalia Cristina Simão da Silva participated in the design of the research project, literature review, data collection and writing of the article. José Antonio Chehuen Neto supervised and reviewed the project and participated in the formatting and editing of the text. Renato Erothildes Ferreira participated in the research design, statistical analysis and its interpretation.



Appendix

Data collection instrument:

| Socio-demographic profile of the sample | | |
|---|-------------------------------|--|
| 1 | Age in years: | () |
| 2 | Sex: | (1) Female (2) Male |
| 3 | Color: | (1) White (2) Mixed-race (3) Black (4) Yellow (5) Indigenous |
| 4 | Income of interviewee: | (1) Up to double the minimum wage (2) More than double the minimum wages |
| 5 | Religious belief: | (1) Atheist (2) Catholic (3) Evangelic (4) Spiritualist (5) Others |
| 6 | Education: | (1) Technical course (2) Bachelor degree or equivalent (3) Post-graduation course (specialization) (4) Master degree (5) PhD |
| 7 | Marital status: | (1) Single (2) Married (3) Widower (4) Divorced (5) Other |
| 8 | Living arrangements : | (1) Live alone (2) Live with their parents (3) Live with a partner (4) Live in a retirement home (5) Others |
| 9 | Where do you live? | (1) City center (2) South (3) East (4) West (5) North (6) Rural areas |

| Opinion regarding living will (LW) | | |
|------------------------------------|---|--|
| 1 | What is your profession? | (1) Medical Doctor (2) Nurse (3) Nutritionist (4) Psychologist (5) Physiotherapist |
| 2 | Do you work in an intensive care unit? | (1) Yes (2) No |
| 3 | How often do you deal with critically ill patients? | (1) Seldom (2) Often |
| 4 | Do patients often express opinions regarding procedures to which they will be submitted? | (1) Yes (2) No |
| 5 | Do you consider that the professionals are concerned about informing the patient of his/her health condition? | (1) Yes (2) No |
| 6 | Do you believe that the terminal patients tend to be properly informed about their condition? | (1) Yes (2) No |
| 7 | Do you know the concepts: | |
| | Euthanasia? | (1) Yes (2) No |
| | Orthothanasia? | (1) Yes (2) No |
| | Dysthanasia | (1) Yes (2) No |
| 8 | Do you have close relatives or acquaintances with a terminal disease? | (1) Yes (2) No |
| 9 | If you answered "yes", what disease? | (1) COPD (2) Heart Failure (3) Cirrhosis of the liver (4) Cancer (5) Others |
| 10 | Do you know the CFM Resolution 1995/2012? | (1) Yes (2) No |
| 11 | Do you know the definition of a living will (LW)? * | (1) Yes (2) No |
| 12 | Do you consider it a duty of health professionals to inform patients about LW? | (1) Yes (2) No |
| 13 | Do you know how to write a LW? | (1) Yes (2) No |
| 14 | Have you ever attended to any patient who had or who required a LW? | (1) Yes (2) No |
| 15 | Would you feel comfortable in following the determinations of a LW? | (1) Yes (2) No |
| 16 | Are you in favor of the creation of a regulatory law regarding living wills in Brazil? | (1) Yes (2) No |
| 17 | Would you feel safer with the regulation of LWs? | (1) Yes (2) No |
| 18 | In your opinion, is it important to discuss this issue among health professionals? | (1) Yes (2) No |
| 19 | Do you consider important the dissemination of information about LWs in the media? | (1) Yes (2) No |
| 20 | Would you make a living will for yourself? | (1) Yes (2) No |

* Question 11: If the respondent answers "no", the interviewer should briefly explain the living will, enabling the interviewee to have the knowledge to answer questions 12 to 20.