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RESEARCH

Terminality and living will: the knowledge of medical students

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Abstract

With the intent of increase the autonomy of terminal patients the Federal Council of Medicine was created the Resolution 1.995/2012, which allows the living will. With the objective of evaluate the knowledge of medical students from the first to sixth years about concepts and medical conducts in terminally ill patients, this research was conducted in the form of a cross-sectional study, through the application of a questionnaire, which was completed by 348 medical students. From those, 251 (72,1%) correctly identified concepts about conducts in terminally ill patients, but only 23,5% claimed to know and chose correctly the meaning of the living will. Despite the low knowledge, 80, 1% stated that they intend to respect it when they encounter a terminal patient. Further research is needed, as a way of warning at the current medical curriculum and to bring to light discussions of conducts over terminally ill patients and open ways to the humanized medical practice.

Keywords: Personal autonomy. Living wills. Hospice care. Advance directives.

Resumo

Terminalidade e testamento vital: o conhecimento de estudantes de medicina

Visando dar mais autonomia a pacientes terminais, foi criada pelo Conselho Federal de Medicina a Resolução 1.995/2012, que dispõe sobre o testamento vital. Para avaliar o conhecimento dos estudantes de medicina do primeiro ao sexto ano em relação a conceitos e condutas éticas diante de pacientes terminais, foi realizado este estudo transversal, mediante aplicação de questionário a 348 alunos. Destes, 251 (72,1%) identificaram corretamente questões relacionadas a condutas na terminalidade, mas apenas 23,5% demonstraram conhecer o conceito de testamento vital. Apesar do baixo índice, 80,1% afirmaram ter a intenção de respeitá-lo, no caso de pacientes terminais. Pesquisas sobre o assunto são importantes para alertar sobre lacunas nos currículos desses futuros médicos. Além disso, o caráter reflexivo desse tipo de estudo permite trabalhar questões éticas fundamentais para o atendimento humanizado.

Palavras-chave: Autonomia pessoal. Testamentos quanto à vida. Cuidados paliativos na terminalidade da vida. Diretivas antecipadas.

Resumen

Terminalidad y testamento vital: el conocimiento de los estudiantes de Medicina

Con el objetivo de permitir una mayor autonomía a los pacientes terminales el Consejo Federal de Medicina creó la Resolución 1.995/2012 por, que dispone sobre el testamento vital. Con el objetivo de evaluar el conocimiento de los estudiantes de medicina del primero al sexto año en relación a los conceptos y conductas éticas frente a pacientes terminales, se realizó esta investigación, en forma de estudio transversal, a través de aplicación de cuestionario, el cual fue llenado por 348 estudiantes de medicina. De estos, 251 (72,1%) identificaron correctamente conceptos acerca de las conductas en la terminalidad, pero sólo el 23,5% demostraron conocer el concepto de testamento vital. A pesar del bajo conocimiento, el 80,1% afirmó tener la intención de respetarlo cuando se enfrentan a un paciente terminal. Las investigaciones sobre el tema son importantes para alertar sobre fallas en los currículos de estos futuros médicos, además del carácter reflexivo de este tipo de estudio, permitiendo trabajar cuestiones éticas fundamentales para la atención humanizada.

Palabras clave: Autonomía personal. Voluntad em vida. Cuidados paliativos al final de la vida. Directivas anticipadas.

Aprovação Cade 1.643.532

Declaram não haver conflito de interesse.

The growing life expectancy of the population is, among other factors, due to the great development of health technologies that bring together resources capable of prolonging the life span of the population [1]. The main ethical dilemma among physicians, especially among those who deal with patients in the terminal stage, is when to use all available technology and for how long, considering the rights, autonomy and dignity of the individual [2]. There have been several ethical discussions on the subject in recent years, questioning the quality of life of the terminal patient - the one whose condition is irreversible, independent of the treatment, and who has high probability of death in a short time [3].

The development of new diagnostic methods, highly sophisticated treatments and the introduction of new drugs have provided highly complex methods and therapeutic schemes to patients, prolonging their existence, but sometimes with a high cost in human suffering [1].

Orthothanasia is recognized by the Resolution of the Conselho Federal de Medicina – CFM (Brazilian Federal Council of Medicine) 1,805/2006 [4]. It is defined as the suspension of procedures and treatments that prolong the life of the terminal patient, respecting the will of the person or their legal representative [4]. In patients with the possibility of cure, more measures must be taken, even if they bring some degree of suffering, because in this case, beneficence must overcome non-maleficence. What orthothanasia proposes is the restriction of these measures in patients without expectation of cure, a situation in which the principle of non-maleficence should prevail [5].

Dysthanasia violates the principle of non-maleficence, promoting persistent treatment through invasive means that prolong the suffering of these patients [6]. Another practice that is prohibited in Brazil is euthanasia, which consists of acting actively in the natural history of the disease in order to shorten the life of the patient [7]. There is great confusion between these definitions, even among physicians who deal more with the process of dying and death [5], which reveals the scarcity of discussions on the subject.

The CFM resolution still guarantees the necessary care for the quality of life of the patient and their family, preventing and alleviating suffering by identifying and providing early treatment of pain and other physical, social, psychological and spiritual sufferings. This is the concept of palliative care, defined by the World Health Organization (WHO) [8] in 1990 and updated in 2002.

More recently, respect for the autonomy of the patient has been discussed, that is, the right to express opinions, make decisions and act according to personal values and beliefs [9]. This right is provided for in article 15 of the Código Civil (Brazilian Civil Code) and in articles 22, 23 and 24 of the Code of Medical Ethics (CME) [10]. The Anticipated Will Directives (AWD), recognized by CFM Resolution 1995/1995, consist of *a set of wishes previously and clearly expressed by the patient about care and treatments that they wants to receive when they are unable to freely and autonomously express their will* [11].

AWDs follow two methods: the enduring mandate, which consists in the appointment by the patient of a close and trustworthy person to make decisions about health care when unable to manifest his or her will and living will (LW). This, under the legal basis of autonomy, is a document with which the patients themselves determine the procedures and treatments to which they wish to be submitted or not when they are prevented from expressing themselves [12]. It is valid only in situations of termination, while the term of office is legitimate in temporary situations of incapacity [1].

The basis of the LW is practically the same as those of the informed consent, since it is the patient's will when, at the critical moments of their life, they must undergo the intervention without being able to express themselves and give consent [13]. Some authors question the term "living will", since it refers to a civil will, a document that only becomes valid after death [14].

In contrast to the United States and certain European countries, which already have legal bases, in Brazil physicians must comply with CFM Resolution 1995/2012, but still without legal protection [15]. In addition, CFM Resolution 1,805/2006 was suspended by the Ministério Público – MP (Public Prosecutor's Office) on the grounds that discontinuation of treatment would be equivalent to passive euthanasia.

This impediment was considered unfounded by the 14th Federal Court in 2010, when the resolution returned to force [6]. The lack of precise legislation on the free will of the terminally ill patient reflects the lack of information on the subject in society and the insecurity among physicians in relation to orthothanasia and LW [16].

Given this scenario of ignorance and insecurity about the LW, it is important to evaluate the knowledge and attitudes regarding these issues among medical students in order to identify possible gaps in the curricula of these future physicians and to work ethical issues that are fundamental to humanized care.

Therefore, the general objective of this study was to analyze the knowledge of students from the first to sixth year of medical school at the Positivo University in 2016 on the concepts of terminality (orthothanasia, dysthanasia, euthanasia, palliative care) and the LW, as well as resolutions of the CFM that base the orthothanasia and the AWD, verifying how many students learned about the subject in the curriculum. Specific objectives include assessing students' conduct toward terminally ill patients and verifying whether variables such as gender, age, and religion influence this issue.

Methods

A quantitative, cross-sectional, descriptive study of prospective data collection using a questionnaire with medical students from the first to sixth year of the Positivo University in 2016. Data collection was performed between July and October 2016, after approval by the ethics committee of the Positivo University.

The questionnaire addressed personal data (sex, age, religion and course year) and had six questions involving concepts about termination of life (euthanasia, orthothanasia, dysthanasia and palliative care), LW and CFM resolutions. In addition, there was a question about the opportunity to discuss the subject during graduation and four questions of opinion: if the interviewee considered it to be the health professional's responsibility to guide terminal patients on LW; if the LW of a terminal patient would be respected (if it complied with the precepts dictated by the Code of Medical Ethics); if publicity in the media about LW was considered important; if the interviewee would make an LW for him/herself.

Participants signed two copies of the free informed consent form (FICF), one for the researchers and the other for themselves. The anonymity of the students was guaranteed, according to the ethical principles of the research. The inclusion criteria were: students who signed the FICF and students who were attending medical school at Positivo University in 2016 (from the first to the sixth year). Students under 18 years of age were excluded from the study, those who refused to complete the questionnaire and those who left it incomplete or filled it incorrectly.

Statistical analysis was based on means and standard deviation and univariate analysis by Fisher's exact test and chi-square test, considering significance level ($p < 0.05$).

Results

The total number of students who completed the questionnaires was 357, with eight having been excluded for being under the age of 18, and one for inadequate completion, totaling n = 348. The mean age of participants was 22.1 ± 3.4 years, 53% female and 34.2% male (44 respondents did not specify sex). About religion, 81% of them claimed to follow one, with prevalence of Catholics (57%); 19% declared themselves to be atheists, agnostics or without a specific religion.

When asked about the terminology concepts, the proportions of correct answers were 72.4%, 85.6%, 85% and 97.4%, respectively. Of the total, 251 (72.1%) students got all of these concepts correctly, with this rate increasing between the 1st and 3rd year (from 58.5% in the 1st to 78.5% in the 3rd), decreasing in the 4th and 5th years (69.6% and 75%, respectively), and the 6th year reaching 96.2% ($p = 0.00863$, by the chi-square test). Regarding CFM Resolution 1,805/2006 dealing with orthatanasia, only 6% claimed to know about it.

Among the students who had full discernment over the four concepts, 209 (83.2%) answered that the option for the terminal patient, without the possibility of LW, is orthatanasia (14 participants did not answer the question). As in the previous question, we also observed an increasing rate from the 1st to the 3rd year: 63.1% and 89%, respectively, with decreases in the 4th year (81.8%), and 5th and 6th years reaching 100%. There was no statistical difference between the sexes ($p = 0.105$, by the chi-square test), nor among those who follow a religion ($p = 0.276$, by the chi-square test).

The understanding of the LW, according to the year of medical school, is shown in Table 1. Most of the students affirm that they do not know the concept (69.8%). Among those who stated that they understood it, it was verified how many got the definition correctly in the question that presented four options of answers. Those considered to be correct were those that exclusively marked the option "*Document representing the manifestation of the will of the testator, whose effects will be produced before his/her death, through which he/she will establish the procedures and treatments to which he/she wishes or not to be submitted, when he/she is unable to express him/herself*". The full comprehension rate of the LW found was 23.5%.

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Table 1. Distribution of the number of students who are familiar with the LW concept, according to their year in medical school.

Year (n)	State the know	%	Correct *	%
1º (n=65)	15	23	11	16.9
2º (n=68)	17	25	12	17.6
3º (n=70)	23	32,8	17	24.3
4º (n=79)	30	37,9	23	29.1
5º (n=40)	12	30	11	27.5
6º (n=26)	8	30,7	8	30.7
Total (n=348)	105	30,1	82	23.5

**Chi-square test: p = 0,3715*

According to age, 28.8% of participants aged 18 to 24 knew the definition of LW. For participants aged 25-50, this rate was 33.3%, but there was no statistical difference (p = 0.646, by Fisher's exact test). After the analysis, the interviewees who did not know the concept of LW were informed of what it was.

Most of the participants (77.6%) stated that they did not have the opportunity to discuss the topic during medical school. Only 42.6% of students who know what LW is and 33.5% of those who do not know have said they have discussed the subject in the classroom. Graph 1 shows this proportion of students, according to the year of the course.

Over 95% stated that it is important to divulge the theme in the media. Regarding the opinion that it is the responsibility of the health professional to guide the existence of the document, 96.5% of the interviewees agreed with this statement. However, regarding CFM Resolution 1995/12, most said they did not know it (91.9%), and 86.7% would not know how to legally express the LW. Only 22 out of the 82 who were aware of what the LW was about (26.8%) said they could guide the patient on how to write it.

When asked about the hypothesis of dealing with the terminal patient presenting LW, 279 (80.1%) would respect the patient's decision in this case. The positive response to the intention to write an LW for oneself was higher (92%). For this question there was more balance between the sexes and between those who follow a religion or not, but without statistical significance. Table 2 shows the association between these issues.

Graph 1. Distribution of the number of students who claimed to discuss the LW theme in medical school, according to their year in medical school

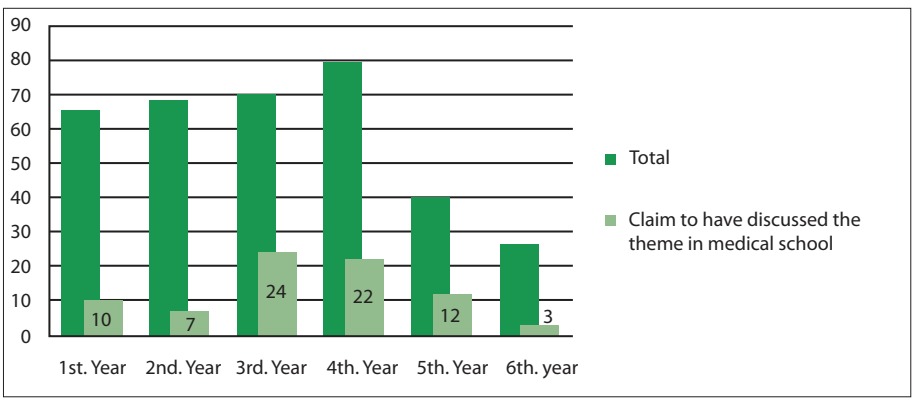

Table 2. Distribution of the number of students who would respect the terminal patient's LW according to gender and religion

Variable	Yes	No	*p* value
Respect to the terminal patient's LW			
Sex			
Feminine (n = 185) Masculine (n = 119) Total (n = 304)	150 (81%) 93 (78%) 243 (80%)	35 (19%) 26 (22%) 61 (20%)	0.559
Religion			
Yes (n = 282) No (n = 66) Total (n = 348)	222 (79%) 57 (86%) 279 (80%)	59 (21%) 9 (14%) 68 (20%)	0.227

continues...

Table 2. Continuation

Variable	Yes	No	*p* value
Intention to write one's own LW			
Sex			
Feminine (n = 185)	172 (93%)	13 (7%)	
Masculine (n = 119)	110 (92%)	9 (8%)	1.000
Total (n = 304)	282 (93%)	22 (7%)	
Religion			
Yes (n = 282)	262 (93%)	20 (7%)	
No (n = 66)	59 (89%)	7 (11%)	0.315
Total (n = 348)	321 (92%)	27 (8%)	

Discussion

First, it is necessary to evaluate the knowledge about the bases of bioethics among students. In this study it was shown that 251 (72.1%) correctly correlated all terminality concepts with the respective description, and there were two correctness peaks during the course: the first at the beginning of the clinical cycle (3rd year - 78.5%) and another in the last year (96.2%).

In another study [12], the concept of orthothanasia was the best known among physicians (96.3%), followed by euthanasia (74.8%) and dysthanasia (58.5%). In this case, the most confusing concept was orthatanasia (only 72.4% accuracy), a result similar to that of Vasconcelos, Imamura and Villar [5], in which, even among intensive care physicians, oncologists, geriatricians, and other specialists which deal more with the dying process, orthatanasia was the less widespread term with 79.5% knowledge. Among the 251 students who understood the four concepts, 209 (83.26%) would opt for orthatanasia if they did not know the patient's wishes. In two other Brazilian studies [5,15], 92.8% would also opt for orthothanasia in the situation.

Only 6% of students were aware of CFM Resolution 1,805/06, but among the 327 who did not know it, the majority (68.5%) would practice orthothanasia in the case of a terminally ill patient. A similar result was found: 56% of doctors who did not know the document already practiced orthothanasia [5]. However, a direct correlation was observed between orthothanasia and resolution awareness, in addition to being related to the non-acceptance and non-performance of dysthanasia [5].

To guarantee the autonomy of the terminal patients, the LW was created as a AWD tool. Among the academics, 30.1% stated that they had contact with the document, and 23.5% actually showed it, marking the most correct and complete definition of the four options presented. We observed a progressive rate in this issue according to the year of the course, with the highest achievement rates in the 4th and 6th years (29.1% and 30.7%, respectively) and a slightly lower rate in the 5th year (27.5%).

The literature presents disparate results in this domain, varying between 8% [16] and 29% [15]. This large difference can be associated to the curricular approach of the courses. The results are similar to those of the present study: only 24.6% of physicians fully understand the definition of AWD [17]. In other studies, there is also a lack of knowledge about the subject in the population as a whole: 94,5% of patients did not know anything about LW [13].

Teixeira and colleagues [18] observe that age is a determining factor when it comes to anticipated will directives. In our study, 28.8% of participants aged 18 to 24 knew the definition of LW. The rate rises to 33.3% among those aged 25-50, but there was no statistical difference due to the small sample size of the latter group.

It is interesting to note that CFM Resolution 1,805/2006 is even less widespread (6%) among students than 1,995/2012 (7.75%), so it is possible to infer that the time that the resolutions are in force does not influence in this case. Knowledge about the latest resolution among trained doctors is about 18% [12]. The suspension of CFM Resolution 1805/2006 by the MP for 4 years may be the main factor that interfered in the disclosure of the document.

We can see the great acceptance of the LW among medical students, as 80.1% of the sample analyzed would alter the patient's treatment to respect his/her wishes, a result similar to those of other studies [15,16]. However, among practicing physicians, acceptability falls to 47.6% 12, with 83% saying that specific legislation would give more security to apply the document.

In our study, the reason for not accepting the LW was not asked, but interesting data were

observed: 92% of the students stated that they would make a living will, against 80.1% that would respect the patients' wishes. This difference is corroborated by the literature: while 47.6% of physicians would agree to accept the patient's choice in the LW, 61.8% stated that they would have the document made for themselves [12], since it corroborates the hypothesis of apprehension about lack of legal support due to a lack of law with the support of the National Congress [6]. Regarding respect for the living will, Simón-Lorda and colleagues [19] suggest that primary care physicians are more open to compliance with AWD when compared to specialized care. However, more studies are needed to better explain this difference.

In addition to the influence of legal issues on both LW knowledge and acceptance, there are sociodemographic factors such as sex, gender, age, ethnicity, religion, education, and income. In our research, income and ethnicity were not analyzed, but several studies demonstrate the interference of these aspects. Huang, Neuhaus and Chiong [20] suggest that older black and Hispanic Americans tend to be less open to AWD.

Some researches with physicians also point out that the receptivity of these directives varies widely between countries: 31-55.3% among Japanese doctors [21,22], 39% for British geriatricians [23] and 90.4% among the Spanish [19], for example. Regarding the financial and educational aspects, the higher the income and the higher the schooling, the greater the tendency for discussion and the practice of AWD [18]. The higher income also seems to be a factor associated with the acceptance of orthothanasia [24].

Some authors argue that sex can affect attitudes and opinions about AWD: women are, in general, more willing to discuss and more engaged in the practice of the AWD [18,20,25]. In our research, there was no difference between the sexes about the desire to do LW for themselves, as in the study by Schiff, Rajkumar and Bulpitt [26].

As for the patient's living will, 81% of the women and 78% of the men answered that they would respect it, but there was no statistically significant difference. Velasco-Sanz and Rayón-Valpuesta found a different result, with 81.8% of the men responding that they would follow the LW in an emergency, compared to 65.8% of the women, a statistically significant difference [27]. There is some conflicting data in the literature on the opinion of men and the influence of religion: whereas for some authors they and individuals without religion are more prone to dysthanasia [24], for others, these same groups were more favorable to euthanasia and assisted suicide [28]. In the present study, there was no statistical difference between the sexes and between religious and non-religious in relation to the opinion favoring the practice of orthothanasia, as well as questions about living will.

Despite the agreement of 96.5% of the interviewees that the health professional should be responsible for the LW orientation, 86.7% said they did not know how to do it. Other studies also show the unpreparedness of medical students to deal with terminality issues [29-31]. However, it is necessary to admit that this does not happen only with students: 90.3% of intensive care physicians and nurses do not know all the measures provided for by the AWDs [27].

Only 22.4% of the participants stated that they had discussed terminality and LW during undergraduate and, through the analysis of these data, there was an improvement of the emphasis on the subject in the discipline of bioethics at the university studied in recent years. It was found that 34.3% of the 3rd year students, that is, those who have just finished the bioethics course, reported having had contact with the subject in the undergraduate program, compared to only 11.8% of the students at the end of medical school.

From these data it can be concluded that the discussion about the subject during the basic cycle is valid and important, but not sufficient, since it is a period in which the student is relatively distant from the clinical practice [32]. Students in the 4th. and 5th. years were less successful (compared to the previous period) in questions about terminology concepts and LW, respectively. This shows that these subjects should be continuously discussed during the course, with different approaches, according to the year.

The differences between euthanasia, dysthanasia and orthothanasia must be addressed throughout the course, as they involve important ethical reflections. The teaching of AWDs must begin in the basic cycle, but the legal background and practical knowledge on how to write and apply the living will can be provided when the student has greater daily contact with terminal patients, usually in the last two years of the course. This would make them safer, preventing only 16.6% of students from completing medical school knowing how to guarantee the legal value of the will.

Several articles show the positive experience of courses that included the discussion of the theme in the curriculum in different ways, such as online interactive exercises [33], teaching by skills [34] and discussion in small groups [35]. Regardless of how

the subject is discussed, all these reports reveal a positive impact on students' lives, especially as an opportunity to develop communication skills [33-35].

Final considerations

The present study aimed to identify the knowledge and perception of medical students about ethical decisions in the termination of life and the living will. The results show that most of them (72.1%) can differentiate euthanasia, dysthanasia and orthothanasia, but the knowledge about LW and the resolution of CFM that supports it is reduced (23.5% and 8.1%, respectively) . Only 22.4% of the students had contact with the subject in medical school. Regarding ethical decisions, 83.2% of respondents favor orthatanasia and 80.1% would respect the LW of the patient.

The study is validated not only in the way it evaluates the perception of future physicians about the subject, allowing discussion about ethical decisions in relation to patients, but it also involves the informative and reflective nature of the research to the interviewees and readers, regarding the advance directives themselves.

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Research

Anex

Survey Instrument

1. Sex: Masculine ( ) Feminine ( ) Age: ___ years
2. Year in medical school: _____
3. Religion: Catholic ( ) Spiritist ( ) Evangelical ( ) Atheist ( ) Other ( ). Which? _____
4. Number the columns:

   1. Euthanasia
   2. Dysthanasia
   3. Orthothanasia
   4. Palliative care

	Suspension of medicinal or artificial means of life of a patient in irreversible coma and considered in "brain death", when there is serious impairment of the coordination of the vegetative life.
	Conduct to promote death of an incurable patient and in unbearable suffering sooner than is expected.
	Assistance measures aimed at improving the quality of life of patients and their families who are facing life-threatening illnesses through the prevention and relief of suffering, the identification and early treatment of pain and other physical, social, psychological and spiritual symptoms.
	An insistent, unnecessary and prolonged treatment of a terminal patient, who is not only "unsavable", but also subjected to futile treatment.

5. Do you know CFM Resolution 1,805/2006 about orthothanasia?

   ( ) Yes ( ) No
6. What would be your conduct facing a terminal patient, without the possibility of a living will?

   ( ) Euthanasia ( ) Distanásia ( ) Ortotanásia
7. Do you know CFM Resolution 1,995/2012 about anticipated will directives?

   ( ) Yes ( ) No
8. Do you know the concept of living will?

   ( ) Yes ( ) No
9. Which of the following do you consider to be correct for the concept of living will?

   ( ) Appointment, by the patient, of someone close and reliable to make decisions about his or her health care when unable to manifest his or her will.

   ( ) Document representing the manifestation of the will of the testator, whose effects will be produced after his death, and with which he will establish the donation of organs.

   ( ) Document representing the manifestation of the will of the testator, whose effects will be produced before his/her death, through which he/she will establish the procedures and treatments to which he/she wishes or not to be submitted, when he/she is unable to express him/herself.

   ( ) Document representing the manifestation of the last will of the testator, whose effects will be produced after his death, and with which will establish the destination of the assets of his patrimony.

   **Here, the examiner must explain the concept of living will.
10. During medical school, have you had the opportunity to discuss about "living will"?

    ( ) Yes ( ) No
11. Do you consider it the responsibility of the health professional to guide terminally ill patients about the living will?

    ( ) Yes ( ) No
12. Would you change the treatment of the patient to respect the living will if it did not disagree with the precepts dictated by the Code of Medical Ethics?

    ( ) Yes ( ) No
13. Would you be able to guide the patient on how to legal manifest the living will?

    ( ) Yes ( ) No
14. Do you think it is important to publicize the living will in the media?

    ( ) Yes ( ) No
15. Would you have a living will for yourself?

    ( ) Yes ( ) No

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