

Patient's rights to advance directives

Maria Aparecida Scottini¹, José Eduardo de Siqueira², Rachel Duarte Moritz³

Abstract

This research identified the knowledge that 55 patients with terminal diseases had about their diagnosis, prognosis, and the option to register their end-of-life will in advanced directives. Among the studied subjects, only one had already registered their advance directives; three of them expressed their interest in registering them after dialogue with the researcher. All the others subjects stated that they did not have the opportunity to discuss the matter. Decisions regarding patients' end of life invariably make evident the lack of clarifying dialogue between doctor and patient. The study data suggest that advance directives, although constituting an instrument for the respect for the autonomy of will of patients with terminal diseases, are far from being effective in practice, which leads to the need to improve the communication between doctors and patients regarding the process of reaching the end of life.

Keywords: Hospice care. Advance directives. Bioethics.

Resumo

Direito dos pacientes às diretivas antecipadas de vontade

Este estudo investigou o conhecimento que 55 pacientes com doenças terminais tinham sobre seu diagnóstico, prognóstico e a possibilidade de registrar seus desejos no final de vida sob a forma de diretivas antecipadas de vontade. Dos sujeitos da pesquisa, apenas um a havia registrado, e três deles, após diálogo com a pesquisadora, manifestaram interesse em formalizá-las. Os demais declararam não ter tido oportunidade de conversar sobre o tema. As decisões sobre o final da vida do enfermo invariavelmente evidenciam a subestimação de diálogo esclarecedor entre médico e paciente. Os dados do estudo sugerem que as diretivas antecipadas, embora façam parte do respeito à autonomia de vontade dos pacientes com doenças terminais, estão longe de serem efetivadas na prática, o que leva à necessidade de melhorar a comunicação entre médicos e pacientes sobre o processo de terminalidade da vida.

Palavras-chave: Cuidados paliativos na terminalidade da vida. Diretivas antecipadas. Bioética.

Resumen

Derecho de los pacientes a las directivas anticipadas de voluntad

Este estudio investigó el conocimiento que 55 pacientes con enfermedades terminales tenían sobre su diagnóstico, su pronóstico y sobre la posibilidad de registrar sus deseos en el final de la vida bajo la forma de directivas anticipadas de voluntad. De los sujetos estudiados, sólo uno había registrado su directiva anticipada y, tres de ellos, después de dialogar con la investigadora, manifestaron interés en formalizarla. Los demás declararon que no habían tenido la oportunidad de conversar sobre el tema. Las decisiones sobre el final de la vida del enfermo evidencian invariablemente la subestimación del diálogo esclarecedor entre médico y paciente. Los datos del estudio sugieren que las directivas anticipadas, aunque formen parte del respeto a la autonomía de voluntad de los pacientes con enfermedades terminales, están lejos de aplicarse en la práctica, lo que conduce a la necesidad de perfeccionar la comunicación entre médicos y pacientes sobre el proceso de terminalidad de la vida.

Palabras clave: Cuidados paliativos al final de la vida. Directivas anticipadas. Bioética.

Aprovação CEP-Unisul 1.193.273

1. **Mestre** mascottini@gmail.com – Universidade do Sul de Santa Catarina (Unisul), Palhoça/SC 2. **Doutor** eduardo.jose@pucpr.br – Pontifícia Universidade Católica do Paraná (PUCPR), Curitiba/PR 3. **Doutora** racheldmoritz@gmail.com – Universidade Federal de Santa Catarina (UFSC), Florianópolis/SC, Brasil.

Correspondência

Maria Aparecida Scottini – Rua General Bittencourt, 502, apt. 904 CEP 88020-100. Florianópolis/SC, Brasil.

Declararam não haver conflito de interesse.

Population aging, related to the demographic transition, is related to the increase in the complexity of chronic degenerative diseases, conditions that require more follow-up, evaluation and long-term interventions^{1,2}. This condition requires new proposals for the home care and palliative care (PC) of these patients³.

Another necessary approach in health care is the humanization of care. Due to the scientific and technological advances to diagnose and treat diseases, patients have often been reduced to their biological dimension, not having their subjectivity considered.

In this context, home care presents itself as an alternative to rescue this dimension of care. The humanization of this aspect requires that allied technoscientific competence and integral patient care of the patient as a biopsychosocial being⁴. PC aims to offer this humanized care in order to improve patients' quality of life, especially in the terminal phase of their lives⁵.

In the context of the ethical foundations of the PC, actions must override those who seek impossible healing. There is also a commitment to the goal of allowing the patient to decide on the treatment that best suits him. Based on the principle of autonomy, the patient must be correctly informed about all possible clinical complications in the course of the disease, thus favoring the attendance of his personal desires in relation to the therapeutic alternatives offered by the professional team⁶.

The major challenge of palliative care is to reconcile the autonomy of patients with terminal illnesses with the therapeutic expectations of the health team⁴, considering that in this case the adequate prognosis proves to be an issue as delicate as it is essential. Important instruments for this evaluation are the Palliative Performance Scale (PPS) 5 and the Mini Mental State Exam (MM), which allow the assessment of the mental functional capacity of the patient, an essential condition for making rational decisions^{7,8}.

Concomitant to the appearance of PC, there was a change in the physician-patient relationship. Traditionally, the professional made all the therapeutic decisions, the patient only had to fulfill them. Coupled with this paternalistic model of the practice of medicine, the second half of the twentieth century recorded extraordinary biotechnological advances, which allowed the indiscriminate use of therapeutic procedures,

which turned the process of dying into an endless suffering for the patient and her/his relatives⁹.

In 1973, the American Hospital Association issued the universally accepted Patient's Bill of Rights¹⁰, which guarantees every patient the right to be fully informed about their illness. In 2009, the new code of medical ethics (CME)¹¹, which went into force in 2010, began to recognize the patient as an autonomous person with the capacity to make decisions. As a result, all institutions involved in health care began to adopt as mandatory practice the obtaining of free and informed consent Form (FICF), preceding any diagnostic or therapeutic procedures performed in humans¹².

More recently, due to the disproportionate use of medical procedures to keep vital data on patients with terminal illnesses and hospitalized in intensive care units (ICUs), the debate has expanded to the adoption of a new instrument called Advance Written Directives (AWD)¹³. This document registers the desires of how sick people would like to be treated in conditions of termination of their life, allowing the patient to lead his/her process of dying and have dignity in that unique moment of one's existence¹³.

The AWD, according to Dadalto¹⁴, are a kind of expression of will which regards future medical care that a person wants to receive and comprehends two documents: the living will and the durable mandate. Patients under PC should be advised of the possibility of having both¹⁴.

The living will originated in the United States and was proposed by Luis Kutner as a document that would allow the patient to refuse certain medical treatments. According to the author, this would protect his rights when his clinical condition was irreversible or in a persistent vegetative state¹⁵. In 1991, the American Congress approved the Patient Self-Determination Act (PSDA), recognizing the patient's right to self-determination and instituting two types of Advance Directives, Living Will (LW) and the Durable Power of Attorney for Health Care (DPAHC)¹⁵.

LW is a document restricted to end-of-life decisions and prevents the performance of treatments when the person is most able to decide. The DPAHC, translated as a "durable mandate," allows the appointment of the person to be consulted in the event of temporary or definitive incapacity to make decisions on medical treatment¹⁵. According to Dadalto, Tupinambás

and Greco¹⁵, this mandate has a broader scope; however, nothing prevents the two documents from coexisting.

From the North American initiatives, European and Latin American countries began to implement similar legislation aimed at protecting the right to autonomy of patients¹⁴. Although the Conselho Federal de Medicina – CFM (Brazilian Federal Council of Medicine) approved Resolution CFM 1995/2012¹⁶, which provides for the AWD, there is no specific legislation on the theme^{15,16}.

The CFM understands as sufficient statement made by the patient to his physician, and it is up to the professional to register in the medical record the decisions verbalized by the patient, that can not undergo any modification, even if they come from family members¹⁶. The CME¹¹ in force in our country protects the right of the patient by ensuring that he/she is adequately informed about his/her illness and the possibility of deciding on treatment, specifying that in cases of incurable and terminal illnesses the physician should offer all available PCs to spare him/her futile or disproportionate procedures¹¹.

This guideline to suspend treatments that unnecessarily prolong the life of the patient with severe and/or incurable illness given to the physician is also provided for in Resolution CFM 1,805/2006¹⁷, a guideline already incorporated in the current CME. In short, there are sufficient indications that support respect for patients' autonomy, which is the ethical guiding principle of AWD¹⁸.

Admittedly, death came to be seen differently in post-modernity. The transfer of the *articulo mortis* to the hospitals, turned it into inconvenience that needs to be hidden. The fact that it was a taboo meant that talking or even thinking about death was a source of shame¹⁹. This change in behavior is also related to the advance of biomedical technology that has displaced the death of households to hospitals, excluding the process of dying of the social sphere and making it solitary¹⁹.

The physician also moved away from the patient, overwhelmed by the feeling of failure to save lives. Therefore, it is imperative to recognize the finitude of life and allow the patient as a biographical being to have a dignified death and "live it" according to her/his own personal values and beliefs²⁰. Driven by these challenges, this study aimed to identify the knowledge of patients under home PC of their own disease and the

possibility of recording their end-of-life wishes from AWDs.

Methods

A cross-sectional and descriptive study in which adult patients over 18 years of age enrolled in a health plan offered by a medical cooperative were evaluated under home PC in the city of Florianópolis, Santa Catarina, Brazil, in 2016. In this plan, PCs are provided at the request of the attending physician and carried out by a multiprofessional team, through home visits, stipulated according to the periodicity established by the professional responsible for the case. At the time of the study, the total number of adult patients under this type of care was 215.

A total of 65 patients were randomly selected to be visited by the researcher in charge. This number was reached from the sampling margin of 10%, with a confidence level of 95% and a maximum percentage of 40%. During the study, 10 patients were excluded either for death and discharge given by the attending physician, thus, 55 patients were evaluated. All the interviews were made by the author of this study between March and August 2016. Assuming the condition of observer, at no time did she provide professional services, a condition that was previously known by all study participants.

All patients signed FICF reporting information that the data collected by the study would be kept confidential. Prior to the initial interview, the researcher phoned all patients to find out whether they would be willing to participate in the study when the visits were scheduled, always at the patient's home. At the first visit, to obtain the FICF of the interviewees, the questionnaire was applied with objective questions about demographic and clinical data. In addition, data were collected for the Palliative Performance Scale (PPS) and Mini Mental State Exam (MM).

The studied variables were knowledge about diagnosis, prognosis and life expectancy of the current disease; patients' opinion about the importance of dialogue with their relatives, physician and care team about the disease and what procedures, according to their personal understanding and values, should be adopted at the end of their lives.

Participants were asked about information they might have received about the possibility of registering end-of-life desires, through the elaboration of personal AWD. Other factors were also questioned, such as whether there was preference

for ICU admission; desire to be reanimated or not in the occurrence of cardiorespiratory arrest; preferably at the time of death (at home or in a hospital setting).

In addition, the researcher encouraged the patients to talk freely about open questions: "were you informed about the diagnosis of your illness?"; "Did you have the opportunity to talk to your physician about the treatment and to see if it could lead to a cure, the evolution of the disease and the life expectancy of the future?"; "Did you talk to anyone about your willingness to define your own treatment in case of incurable disease and the possibility of dying as a result of it?"; if so, "did you make any written or verbal record of how you would like to be treated under that circumstance?"; "In case your illness is severe and incurable, would you wish to be admitted to the ICU?"; "Would you wish to be admitted to the ICU or would you rather die at home?"; "In the event of suffering cardiac arrest would you wish to be revived?"

For the purpose of the statistical analysis of the information obtained, the database was created from the questionnaires applied and exported to the program Statistical Package for the Social Sciences (SPSS), version 18.0. In the descriptive analysis, the qualitative data will be presented in the form of simple and relative frequency. In the comparative analysis of the mental status (MM > 24 or < 24), Fisher's exact test with prevalence ratio (PR) and 95% confidence interval were used in relation to patients' perception of end-of-life conducts. The significance level considered was 95% ($p < 0.05$).

Results and discussion

The clinical-demographic characteristics of the patients that make up the sample are presented in Table 1.

Analyzing the demographic characteristics of the studied group, we noticed that the majority of respondents were women, over 75 years old and with a full elementary school degree. Regarding the PPS, which evaluated the degree of functionality of the patients and prognosis, 46 (84%) were below 50, which means a prognosis of 104 days of life, considering a referential study that investigated the average survival of patients with neoplasia and chronic degenerative diseases²¹. Another study that analyzed only patients with neoplasia revealed survival less than 34 days²², that is, a very short prognosis of life, which emphasizes the need for respectful and responsible dialogue with patients about their final desires.

Table 1. Clinical-demographic characteristics of the patients enrolled in the home service of the specific health plan, Florianópolis/2016

Clinical-demographic characteristics	Patients	
	n	%
Sex		
Female	35	64
Male	20	36
Age		
25-50 y.o.	8	14.5
51-70 y.o.	14	25.5
71-90 y.o.	25	45.5
91-105 y.o.	8	14.5
Schooling		
1-3 years	5	9
4-8 years	15	27
Over 8 years	35	64
Mental capacity/MM*		
MM<24	16	29
MM≥24	39	71
Functionality/PPS**		
PPS≤50	46	84
PPS≥60	9	16
Disease Diagnostic		
Neoplastic	12	22
Chronic degenerative non-neoplastic	43	78

*MM – Mini Mental **PPS – Palliative Performance Scale

Regarding the evaluation of cognitive function, MM, a cut grade of 24 was established, and it was verified that 39 (71%) of the patients were above this value, which shows a satisfactory preservation of their cognitive abilities and adequate mental functional capacity to make decisions. Considering the diagnosis of the underlying disease, it was found that 43 (78%) of the patients had chronic degenerative diseases, which is in accordance with the literature, which, in turn, has also shown an increase in the prevalence of these diseases with the increased human longevity¹.

The results obtained by the research, together with the significant degree of physical impairment of the patients, constitute an interesting scenario for bioethical analysis, considering the autonomy of will and extreme vulnerability of these people at the threshold of life. They are individuals who need medical attention that prioritizes their well-being and respect their histories, a condition that will only be adequately met if the PC has specialized professionals²³.

The degree of knowledge of the patients about diagnosis and prognosis of the diseases that afflict them, as well as the fulfillment of their desires regarding therapeutic procedures and clarifications that they had about AWD are in Table 2.

Table 2. Relationship between end-of-life desires and mental functional capacity

End-of-life desires	Patients MM<24 n(%)	Patients MM≥24 n(%)
Knows the diagnosis		
Yes	12 (75)	39 (100)
No	4 (25)	-
Knows the prognosis		
Yes	7 (44)	37 (95)
No	9 (56)	2 (5)
Dialogue with family about directives		
Yes	-	12 (31)
No	16 (100)	27 (69)
Desire to be admitted to ICU**		
Yes	4 (25)	8 (21)
No	7 (44)	30 (77)
Does not know	5 (31)	1 (2)
Place where wishes to die		
At home	8 (50)	22 (56)
At the hospital	5 (31)	9 (23)
Does not know	3 (19)	8 (21)
Wishes to reanimated in case of CRP***		
Yes	11 (69)	32 (82)
No	2 (12)	5 (13)
Does not know	3 (19)	2 (5)

*MM – Mini Mental **ICU – Intensive Care unit ***CRP – Cardiorespiratory Arrest

The comparative analysis between the mental functional capacity (MM) of the patients and their perceptions about the end-of-life behaviors, from the Fischer test, are presented in Table 3.

The analysis of the data shows that all patients with MM≥24, that is, with preserved mental functions, were fully aware of the diagnosis of the disease that affected them and 95% had been

informed about the unfavorable prognosis of their diseases.

Of the patients with MM < 24, compromised mental functional capacity, only 12 (75%) knew the diagnosis and 7 (44%) knew the prognosis. These facts allow us to conclude that patients with MM ≥ 24 were fully aware of their diagnosis (p = 0.010) and prognosis (p < 0.001) when compared to patients with MM <24. Regarding any dialogues about their wills in the dying process, 12 (31%) of the patients with MM≥24 reported having talked to relatives.

Considering the patients with MM < 24, none of them had a dialogue with the family, which leads us to assume that, although the index of those who talked about it is low, 12 (31%), being in a better mental state predisposes patient to discuss the AWD with relatives (p = 0.017). Another point worth mentioning is the index of 27 (69%) patients who, even with more lucidity and prognostic science of their diseases, were not motivated to perform their AWDs.

This situation demonstrates that our society is still not ready to address the issue of the finitude of life, an issue that is still very present in contemporary culture known as the “denial of death.” We must overcome this taboo and, for that, it is imperative to involve all health professionals and encourage respectful dialogue with the patients’ families, to guarantee dignity to the dying process. Why, even in the face of the imminence of death, patients, family members and doctors do not talk about it? Only one patient in our study had requested AWDs, and three had expressed an interest in them after being informed by the researcher.

Although most patients were aware of the limited prognosis of their lives, they reported that none of their health care providers, including physicians, had informed them about the possibility of expressing personal desires in end-of-life care (in the form of AWD).

Table 3. Comparison between the MM and perceptions about end-of-life conducts

	Patients MM≥24 n (%)	Patients MM<24 n (%)	RP (IC)	p
Knows the diagnosis	39 (100)	12 (75)	1.333 (1.005 -1.769)	0.010
Knows the prognosis	37 (95)	7 (44)	2,168 (1,238-3,798)	<0.001
No dialogue with family about directives	27 (69)	16 (100)	0.692 (0.561- 0.853)	0.017
No desire to be admitted to ICU**	30 (77)	7 (44)	1.758 (0.983-3.145)	0.041
Wishes to die ate home	22 (56)	8 (50)	1.128 (0.643- 1.981)	0.889
Wishes to be revived In case of CRP***	32 (82)	11 (69)	1.193 (0.831-1.713)	0.460

*MM: Mini Mental; **ICU: Intensive Care unit; ***CRP: Cardiorespiratory Arrest

According to Drane and Pessini, the physician *must do what comes from the patient's needs and that the patient is frightened, incapacitated and seeks the physician's help for a human relationship, not just a technical one*²⁴. The physician and the PC team should strive to show the patient that death gives meaning to existence and that his end of life can occur with dignity, without suffering, surrounded by relatives and friends who want to say goodbye²⁰.

Having technical competence is a minimum and necessary obligation for the practice of medicine, which, however, is not enough to meet the demands presented by patients who are at the end of life. In this circumstance it is necessary that the professional be prepared to listen attentively and respectfully to those who suffer in the physical, psychic, social and spiritual dimensions, respecting their personal values and beliefs. At the same time, the professional must provide all the information regarding the prognosis and the therapeutic possibilities, so that the patient can make her/his choices in the most autonomous way possible²⁴.

The difficulty of physicians in maintaining respectful and enlightening dialogue with patients with incurable diseases occurs, among other reasons, by the above mentioned culture of denial of death. However, we can not fail to expose the problems in undergraduate education in subjects related to the medical humanities. In the nineteenth century, Jose de Letamendi, a Spanish pathologist, coined the phrase that expresses the limitations of traditional medical teaching: *the doctor who knows only medicine, does not even know medicine*²⁵.

Death is an ever-present theme in our culture. Ariès¹⁹ shows that human beings react to death according to their historical period. In post-modernity, death was excluded, being transferred from the home to the hospital, partly due to technological progress, but above all because contemporary society illusively believes that technoscience can overcome it. In this way, there is the feeling of failure before death, especially on the part of the doctor, who starts to fight it with a disproportionate use of useless procedures, which leads to dysthanasia (or therapeutic futility), that is, the unreasonable prolongation of the process that only increases the suffering of patients and their families¹⁹.

Elizabeth Kübler-Ross²⁶ argues that death is an integral part of our lives and gives meaning to human existence. According to Kovács²⁰, humanized death, surrounded by family and friends, should be rescued, taking into account the values and beliefs of

the patient. This is because, with the advancement of medical technologies and a medical teaching that privileges the diagnosis and treatment of diseases and underestimates the biopsychosocial and spiritual human reality, it can not be expected that the student is prepared, at the end of the course, to deal with this situation, since he/she was not trained to face the issue of human finitude²⁷. About this, Ariès states that *death must only become the discreet but dignified exit of a serene living being (...) without effort and suffering and finally, without anguish*²⁸.

Bonamigo, Pazini and Putzel²⁹ are categorical in stating that, due to lack of undergraduate training, physicians and other members of the care team are likely to stop discussing and assisting patients to draft documents that expose wills at this final stage. In 1995 a study was published on medical education in the United States, which proved the lack of discussions on issues related to death and the dying process, both in undergraduate and in medical residency programs³⁰.

After a decade, Pinheiro³¹ published a study on subjects not offered to medical students in the last years of the medical school in São Paulo (5th and 6th years) and presented the following results: 83% stated that they had not received information about the care of patients with terminal illnesses; 63% did not have any class or seminar on "how to give bad news"; 76% were unaware of clinical criteria for treating the pain of cancer patients; and for 82% of them, at no point in medical school had the parameter for opioid use been taught.

A study conducted with students from Pará showed that only 8% of medical students had knowledge about the living will. Several other studies on the curriculum of these courses also show the predominant tendency to include subjects related to biotechnology and to leave aside psychological, social and spiritual aspects³²⁻³⁴.

However, despite the results of these surveys, which demonstrate the need to introduce a PC course in medical education, little or nothing has been done to change this in recent years. It is enough to say that, of the 215 medical schools in the country up to August 2015, only four offered this discipline in their curricula³⁵.

Returning to the analysis of the data collected by the study, 30 (77%) of the patients with MM \geq 24 (preserved mental capacity), when considering the intention to be admitted to the ICU, showed to be contrary to this proposal, while for individuals with

MM < 24, the index was only 7 (44%). These figures show that the desire not to be admitted to the ICU is approximately twice as high in patients with better mental status ($p < 0.05$).

Regarding the choice of place of death, whether at home or in the hospital, and the desire to be resuscitated in the event of cardiorespiratory arrest (CRP), there was no difference between the two groups. Although the majority of patients preferred to die at home, paradoxically, in case of cardiac arrest, they expressed their desire to receive the resuscitation procedure, which can only be performed in a hospital setting.

How to understand this apparent paradox? This desire of the patients finds support in two realities: the culture prevalent in our denial of the finitude of life and the obvious lack of dialogue between doctor and patient, since there should be frank and directed conversation to clarify doubts and insecurities of the patients. There are times in contemporary history that medicine has been recognized as a mute art (*muta ars*)³⁶.

All these contradictions reveal a lack of adequate communication between physicians, patients and the family, and it should be emphasized that neither the attending physician nor the professional responsible for the home care provided conditions for dialogue that would allow the discussion of issues related to the finitude of life or the elaboration of AWD. In addition, the precarious physician-patient relationship and the lack of knowledge or insecurity in complying with CFM resolutions and practicing orthothanasia or "good death" are other factors that hinder communication among those involved in this situation.

Marques Filho and Hossne³⁷ consider that the quality of the physician-patient relationship represents the basis of clinical practice and the most important element of the medical act, along with respect for autonomy and the patient's right to receive all the necessary information, to make decisions that fit their personal values. To that end, trust and mutual respect are essential, especially when it comes to such decisions, which require both sides to have a frank dialogue about the risks and benefits of therapeutic procedures. Obviously, family members should participate in all these steps, which requires the physician to play an important role in solving doubts and questions^{14,38,39}.

The American Hospital Association (AHA)¹⁰, in a publication entitled "*The patient care partnership*", defines the rights and responsibilities of hospital

inpatients in the country, such as to receive all information about the treatment of their illness from medical assistants and to have their personal values and beliefs respected. The CME¹¹ in force in Brazil, when dealing with the relationship with relatives and patients, declares that it is forbidden to the physician to disrespect the right of the patient to decide on the treatment and to fail to inform the patient about the diagnosis, prognosis, risks and goals of the treatment.

In the section on human rights, the code of ethics¹¹ warns that the physician is prohibited from not obtaining consent from the patient to intervene or not guaranteeing the patient the right to decide on procedures in his/her body.

The imminence of death favors reflection on the meaning of personal existence. It is the duty of the physician to show solidarity and disposition to mitigate, as far as possible, the enormous suffering experienced by the one who sees the approximation of the inexorable end of his life²⁰. Kübler-Ross²⁶ points out that death is a part of life, like birth and growth, and brings meaning to human life. According to the author, death is the opportunity to know oneself, grow as a human being and realize what is really important in our personal life²⁶.

Thus, the doctor-patient relationship requires a prudent balance between the autonomy of both, in such a way that the pact is based on mutual trust so that therapeutic procedures are preceded by respectful dialogue and implemented with consensual criteria³⁷.

Cortina⁴⁰, referring to the ethics of the professions, qualifies as "virtuous" the one who seeks excellence and departs from mediocrity, always taking into account the morality prevailing in the society in which one is inserted. In this perspective, it will be up to the entire team of health professionals to establish a deliberative process that also considers scientific knowledge and the scale of moral values of patients and their family environment. Thus, it becomes necessary to treat briefly the different meanings that the medical community attributes to the terms euthanasia, dysthanasia and orthathanasia²⁰.

Euthanasia, a practice condemned by Brazilian law, consists in using active procedures to cause the death of the individual. In countries where it is authorized, the legislation emphasizes that, unlike a murder, it occurs at the request of the patient who experiences extreme pain and suffering²⁰. Dysthanasia results from the use of

medical procedures that artificially maintains the patient's life, without there being any possibility of cure, since all the therapeutic efforts employed are admittedly useless and serve only to prolong the agony of terminally ill patients²⁰. Finally, orthothanasia, a practice that is supported by ethics and is recommended by almost all medical entities in the contemporary world, consists in the use of therapeutic procedures that aim to offer relief and comfort to patients with incurable diseases²⁰. It is under the seal of orthothanasia that PCs are enrolled.

The guidelines contained in the CME, as well as the resolutions of the CFM on orthothanasia and AWD, are enlightening to offer ethical support to the conducts that must be adopted by physicians in the conditions of incurable diseases and about the respect to the autonomy of the patients. Likewise, law scholars dealing with matter, such as Dadalto¹⁴, defend a thesis similar to the CFM proposal.

The lack of preparation of the health professionals to deal with terminal patients is revealed in the daily routine of intensive care physicians, as demonstrated by Forte⁴¹ in a study with physicians of the 11 ICUs of the medical complex of the Clinical Hospital of the Faculdade de Medicina da Universidade de São Paulo – FMUSP (University of São Paulo Medical School). The author analyzed the medical conduct defended by physicians of these units in the face of two hypothetical cases of terminal patients. The results showed that 58% of physicians would not engage in dialogue with patients about their therapeutic decisions, even if these patients are lucid, considering these to be solely of personal competence.

In one case, in which the patient had already expressed a desire not to receive invasive procedures, 19% of the physicians considered it unnecessary to attend to the patient's prior manifestation and instituted procedures that, in their view, would be the most appropriate, based on the best clinical practices.

These results point to the difficulty of physicians to accept their limitations as "healers" and also as communicators in situations of conflict⁴¹⁻⁴⁴. It should be emphasized that physicians' fear of legal proceedings directly interferes with end-of-life decisions. On the other hand, the problems faced by patients and family members are directly related to the difficulty of dialogue about the termination of life⁴⁵⁻⁴⁹.

Forte⁴¹ identified, in a previously mentioned study, that several intensive care physicians would

prolong the patient's life, claiming that they would do so for fear of legal proceedings on the part of the patient's relatives, accusing them of omission of relief. However, although there is no specific legislation, there is an understanding in the legal environment that, by limiting or suspending a procedure considered unnecessary or useless, the physician can not be accused of murder^{49,50}.

Silveira, Kim and Langa⁵¹ published a survey to assess the importance of AWD formulated by 3,746 people and concluded that they had their preferences met by the medical team. However, despite the wide recognition and dissemination of directives, especially in countries with Anglo-Saxon culture, a study carried out in 2013 showed that only 26.3% of US citizens had formalized their AWD⁵². In summary, although the skills needed to provide adequate medical care and less suffering at the end of life, cultural barriers and professional education are the main impediments to the realization of the human right to die with dignity.

Final considerations

It can be inferred that doctors providing end-of-life care are not prepared to address issues of death and human finitude, nor to provide guidance to their patients about the right to autonomy through AWD.

Although there is an ethical definition for these procedures in the resolutions of the CFM, a body recognized by law to control professional practice and give guidance to professionals, physicians feel insecure to adopt measures that prevent the practice of dysthanasia, which often prevents the dignified death of patients in this situation.

It is worth mentioning that, although the present study has a small sample, these are people with a private health plan and a satisfactory degree of education, being attended by professionals trained to provide home care, and this presupposes capacity to understand the importance of this prior deliberation.

It would then be necessary to ask: how to change this reality? The apparent contradictions observed in patients' responses, as well as the lack of dialogue with the physician, represent a broader phenomenon of a cultural nature that points to human vulnerability in relation the finitude of life. Kübler-Ross²⁶ shows how difficult it is to face death and dying and all the existential issues we carry throughout our lives.

Faced with these difficulties, the results of this study suggest that health plans should invest more in the training of physicians, aiming at rebuilding the doctor-patient relationship, distanced for different reasons, and encouraging the family to talk more about death. Courses that offer communication skills can help create professional medical skills that result in decisions that respect the human being in biopsychosocial and spiritual aspects.

These trainings and capacity-building courses can motivate clinicians to consider patients' values and attitude toward serious illnesses, assisting them in conducting and understanding the importance of AWDs so that their end-of-life desires are met. Finally, we believe that more robust studies on the subject should be performed, especially with patients assisted by the Sistema Único de Saúde – SUS (Unified Health System).

Paper presented to the PUCPR graduate program in Curitiba, in order to obtain a master's degree in bioethics.

Referências

1. Andraos C, Lorenzo C. Sistema suplementar de saúde e internação domiciliar de idosos na perspectiva da bioética crítica. *Rev. bioét.* (Impr.) [Internet]. 2013 [acesso 20 out 2014];21(3):525-35. Disponível: <https://bit.ly/2HTNBHN>
2. Grudzen CR, Richardson LD, Morrison M, Cho E, Morrison RS. Palliative care needs of seriously ill, older adults presenting to the emergency department. *Acad Emerg Med* [Internet]. 2010 [acesso 1º nov 2014];17(11):1253-7. Disponível: <https://bit.ly/2JXxiPe>
3. Lacerda MR, Giacomozzi CM, Oliniski SR, Truppel TC. Atenção à saúde no domicílio: modalidades que fundamentam sua prática. *Saúde Soc* [Internet]. 2006 [acesso 1º nov 2014];15(2):88-95. Disponível: <https://bit.ly/2LUwF6u>
4. Pessini L, Bertachini L. Ética do cuidado e humanização no mundo da saúde, em especial em final de vida. In: Pessini L, Bertachini L, Barchifontaine CP, organizadores. *Bioética, cuidado e humanização*. São Paulo: Loyola; 2014. p. 283-308.
5. Maciel MGS. Definições e princípios. In: Oliveira RA, coordenador. *Cuidado paliativo*. São Paulo: Cremp; 2008. p. 15-32.
6. Matsumoto DY. Cuidados paliativos: conceitos, fundamentos e princípios. In: Carvalho RT, Parsons HA, organizadores. *Manual de cuidados paliativos ANCP* [Internet]. 2ª ed. São Paulo: ANCP; 2012 [acesso 1º nov 2014]. p. 23-30. Disponível: <https://bit.ly/2IT7S6B>
7. Folstein MF, Folstein SE, McHugh PR. Mini-mental state: a practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res* [Internet]. 1975 [acesso 10 out 2014];12(3):189-98. Disponível: <https://bit.ly/2lcREGt>
8. Almeida OP. Mini exame do estado mental e o diagnóstico de demência no Brasil. *Arq Neuropsiquiatr* [Internet]. 1998 [acesso 18 out 2014];56(3B):605-12. Disponível: <https://bit.ly/2MroH5P>
9. Siqueira JE, Pessini L, Siqueira CE. Conflitos morais sobre a terminalidade da vida: aspectos médicos, filosóficos e jurídicos. *Rev Colomb Bioét* [Internet]. 2013 [acesso 3 nov 2016];8(2):104-15. Disponível: <https://bit.ly/2JGep4j>
10. American Hospital Association. *The patient care partnership: understanding expectations, rights and responsibilities* [Internet]. Washington: AHA; 2003 [acesso 2 nov 2016]. Disponível: <https://bit.ly/2HVUXum>
11. Conselho Federal de Medicina. Resolução CFM nº 1.931, de 17 de setembro de 2009. Aprova o Código de Ética Médica [Internet]. *Diário Oficial da União*. Brasília; p. 173, 13 out 2009 [acesso 30 out 2014]. Seção 1. Disponível: <https://bit.ly/2uTCahw>
12. Conselho Nacional de Saúde. Resolução CNS nº 466, de 12 de dezembro de 2012. Aprova diretrizes e normas regulamentadoras de pesquisas envolvendo seres humanos [Internet]. *Diário Oficial da União*. Brasília; 13 jun 2013 [acesso 30 out 2016]. Disponível: <https://bit.ly/20ZpTyq>
13. Claudino AHA. A efetividade das diretivas antecipadas de vontade no ordenamento jurídico brasileiro. *Revista Pensar Direito* [Internet]. 2014 [acesso 17 maio 2015];5(1):1-24. Disponível: <https://bit.ly/2Mw5AHN>
14. Dadalto L. *Testamento vital*. 3ª ed. São Paulo: Atlas; 2014.
15. Dadalto L, Tupinambás U, Greco DB. Diretivas antecipadas de vontade: um modelo brasileiro. *Rev. bioét.* (Impr.) [Internet]. 2013 [acesso 18 maio 2015];21(3):463-76. Disponível: <https://bit.ly/2JQ0dC3>
16. Conselho Federal de Medicina. Resolução CFM nº 1.995, de 9 de agosto de 2012. Dispõe sobre as diretivas antecipadas de vontade dos pacientes [Internet]. *Diário Oficial da União*. Brasília; p. 269-70, 31 ago 2012 [acesso 30 out 2014]. Seção 1. Disponível: <https://bit.ly/207VBbw>
17. Conselho Federal de Medicina. Resolução CFM nº 1.805, de 9 de novembro de 2006. Na fase terminal de enfermidades graves e incuráveis é permitido ao médico limitar ou suspender procedimentos e tratamentos que prolonguem a vida do doente, garantindo-lhe os cuidados necessários para aliviar os sintomas que levam ao sofrimento, na perspectiva de uma assistência integral, respeitada a

- vontade do paciente ou de seu representante legal [Internet]. Diário Oficial da União. Brasília; p. 169, 28 nov 2006 [acesso 30 out 2014]. Seção 1. Disponível: <https://bit.ly/1URTI3S>
18. Ribeiro DC. Autonomia: viver a própria vida e morrer a própria morte. Cad Saúde Pública [Internet]. 2006 [acesso 30 out 2014];22(8):1749-54. Disponível: <https://bit.ly/2JQdIRZ>
 19. Ariès P. O homem diante da morte. São Paulo: Editora Unesp; 2014.
 20. Kovács MJ. A caminho da morte com dignidade no século XXI. Rev. bioét. (Impr.) [Internet]. 2014 [acesso 23 out 2014];22(1):94-104. Disponível: <https://bit.ly/2HPorU1>
 21. Lau F, Maida V, Downing M, Lesperance M, Karlson N, Kuziemy C. Use of the palliative performance scale (PPS) for end-of-life prognostication in a palliative medicine consultation service. J Pain Symptom Manage [Internet]. 2009 [acesso 30 out 2016];37(6):965-72. Disponível: <https://bit.ly/2JSj92R>
 22. Weng LC, Huang HL, Wilkie DJ, Hoenig NA, Suarez ML, Marschke M *et al.* Predicting survival with the palliative performance scale in a minority-serving hospice and palliative care program. J Pain Symptom Manage [Internet]. 2009 [acesso 30 out 2016];37(4):642-8. Disponível: <https://bit.ly/2t6Dc7l>
 23. Pessini L, Ricci LAL. Mistanásia: um novo conceito bioético que entra na agenda da bioética brasileira. In: Siqueira JE, Zoboli E, Sanches M, Pessini L, organizadores. Bioética clínica. Brasília: CFM; 2016. p. 95-122.
 24. Drane J, Pessini L. Bioética, medicina e tecnologia: desafios éticos na fronteira do conhecimento humano. São Paulo: Loyola; 2005. p. 62.
 25. Letamendi J. Clínica general. Madrid: Prensa de la Universidad de Madrid; 1894. p. 57.
 26. Kübler-Ross E. Death: the final stage of growth. New York: Touchstone; 1986.
 27. Brugugnoli ID, Gonsaga RAT, Silva EM. Ética e cuidados paliativos: o que os médicos sabem sobre o assunto? Rev. bioét. (Impr.) [Internet]. 2013 [acesso 20 out 2014];21(3):477-75. Disponível: <https://bit.ly/2le7CQA>
 28. Ariès P. Op. cit. p. 827.
 29. Bonamigo EL, Pazini AM, Putzel EL. O papel dos profissionais da saúde nas diretivas antecipadas de vontade. In: Dadalto L, organizadora. Bioética e diretivas antecipadas de vontade. Curitiba: Prismas; 2014. p. 249-72.
 30. Hill TP. Treating the dying patient: the challenge for medical education. Arch Intern Med [Internet]. 1995 [acesso 24 nov 2016];155(12):1265-9. Disponível: <https://bit.ly/2LRytx8>
 31. Pinheiro TRSP. Avaliação do grau de conhecimento sobre cuidados paliativos e dor dos estudantes de medicina do quinto e sexto anos. O Mundo da Saúde [Internet]. 2010 [acesso 2 nov 2016];34(3):320-6. Disponível: <https://bit.ly/2J0XfNH>
 32. Oliveira JR, Ferreira AC, Rezende NA. Ensino de bioética e cuidados paliativos nas escolas médicas do Brasil. Rev Bras Educ Med [Internet]. 2013 [acesso 20 out 2016];37(2):285-90. Disponível: <https://bit.ly/2tcm3lr>
 33. Camargo A, Almeida MAS, Morita I. Ética e bioética: o que os alunos do sexto ano médico têm a dizer. Rev Bras Educ Med [Internet]. 2014 [acesso 2 nov 2016];38(2):182-9. Disponível: <https://bit.ly/2lajd2U>
 34. Bifulco VA, Iochida LC. A formação na graduação dos profissionais de saúde e a educação para o cuidado de pacientes fora de recursos terapêuticos de cura. Rev Bras Educ Med [Internet]. 2009 [acesso 20 out 2016];33(1):92-100. Disponível: <https://bit.ly/2Mw5qAv>
 35. Pessini L, Siqueira JE. Reflexões bioéticas sobre a vida e a morte na UTI. In: Siqueira JE, Zoboli E, Sanches M, Pessini L, organizadores. Bioética clínica. Brasília: CFM; 2016. p. 229-52.
 36. Siqueira JE. Educação em bioética no curso de medicina. O Mundo da Saúde [Internet]. 2005 [acesso 2 nov 2016];29(3):402-10. Disponível: <https://bit.ly/2LVCRuZ>
 37. Marques Filho J, Hossne WS. A relação médico-paciente sob a influência do referencial bioético da autonomia. Rev. bioét. (Impr.) [Internet]. 2015 [acesso 2 nov 2016];23(2):304-10. Disponível: <https://bit.ly/2JRuH6a>
 38. Sousa ATO, França JRFS, Santos MFO, Costa SFG, Souto CMRM. Cuidados paliativos com pacientes terminais: um enfoque na bioética. Rev Cuba Enferm [Internet]. 2010 [acesso 20 out 2015];6(3):123-35. Disponível: <https://bit.ly/2HRMAQD>
 39. Ribeiro HG, Saporetto LA, Carvalho RT. Diretivas antecipadas de vontade e cuidados paliativos. In: Dadalto L, organizadora. Bioética e diretivas antecipadas de vontade. Curitiba: Prismas; 2014. p. 67-84.
 40. Cortina A. Cidadania civil: universalizar a aristocracia. In: Cortina A. Cidadãos do mundo para uma teoria da cidadania. São Paulo: Loyola; 2005. p. 105-38.
 41. Forte DN. Associações entre as características de médicos intensivistas e a variabilidade no cuidado ao fim de vida em UTI [tese]. São Paulo: Universidade de São Paulo; 2011.
 42. Santos MFG, Bassit DP. Terminalidade da vida em terapia intensiva: posicionamento dos familiares sobre ortotanásia. Rev Bras Ter Intensiva [Internet]. 2011 [acesso 30 out 2016];23(4):448-54. Disponível: <https://bit.ly/2sZoCye>
 43. Schaefer KG, Chittenden EH, Sullivan AM, Periyakoil VS, Morrison LJ, Carey EC *et al.* Raising the bar for the care of seriously ill patients: results of a national survey to define essential palliative care competencies for medical students and residents. Acad Med [Internet]. 2014 [acesso 20 out 2016];89(7):1024-31. Disponível: <https://bit.ly/2J0XzMu>

44. McKinlay E, McBain L, Stanley J, Taylor EJ, Robertson G. Does multimodal palliative care education help medical students talk with patients at end-of-life? *FoHPE* [Internet]. 2014 [acesso 20 out 2014];15(3):64-80. Disponível: <https://bit.ly/2HTBDxY>
45. Graneck L, Krzyzanowska MK, Tozer R, Mazzotta P. Oncologist's strategies and barriers to effective communication about the end of life. *J Oncol Pract* [Internet]. 2013 [acesso 26 out 2016];9(4):e129-35. Disponível: <https://bit.ly/2JFdYqW>
46. Abdul-Razzak A, Sherifali D, You J, Simon J, Brazil K. Talk to me: a mixed methods study on preferred physician behaviours during end-of-life communication from the patient perspective. *Health Expect* [Internet]. 2016 [acesso 23 out 2016];19(4):883-96. Disponível: <https://bit.ly/2t1qQNr>
47. Periyakoil VS, Neri E, Kraemer H. No easy talk: a mixed methods study of doctor reported barriers to conducting effective end-of-life conversations with diverse patients. *PloS One* [Internet]. 2015 [acesso 25 out 2016];10(4):e0122321. Disponível: <https://bit.ly/2t1M8ur>
48. Huang HL, Cheng SY, Yao CA, Hu WY, Chen CY, Chiu TY. Truth telling and treatment strategies in end-of-life care in physician-led accountable care organizations: discrepancies between patients' preferences and physicians' perceptions. *Medicine* [Internet]. 2015 [acesso 20 out 2016];94(16):e657. Disponível: <https://bit.ly/2yeVI2l>
49. Moritz RD, Deicas A, Rossini JP. Cuidados paliativos nas UTIs: definições e aspectos ético-legais. In: Moritz RD, organizadora. *Cuidados paliativos nas unidades de terapia intensiva*. São Paulo: Atheneu; 2012. p. 19-31.
50. Vidal SM. Decisiones en el final de la vida: una aproximación desde la bioética [Internet]. 2012 [acesso 1º nov 2014]. Disponível: <https://bit.ly/2K0BZrT>
51. Silveira MJ, Kim SY, Langa KM. Advance directives and outcomes of surrogate decision making before death. *N Engl J Med* [Internet]. 2010 [acesso 20 out 2016];362(13):1211-8. Disponível: <https://bit.ly/2t9pCiB>
52. Rao JK, Anderson LA, Lin FC, Laux JP. Completion of advance directives among U.S. consumers. *Am J Prev Med* [Internet]. 2014 [acesso 20 out 2016];46(1):65-70. Disponível: <https://bit.ly/2LVdgCq>

Participation of the authors

Maria Aparecida Scottini formulated the initial hypothesis and interviewed the patients. José Eduardo de Siqueira and Rachel Duarte Moritz guided the research and made the final corrections to the text.

